




# Self-Reported Hidradenitis Suppurativa Severity: Is It Useful for Clinical Practice?

Piotr K. Krajewski · Servando E. Marrón · Lucía Tomas Aragones ·  
Yolanda Gilaberte-Calzada · Jacek C. Szepietowski 

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## ABSTRACT

**Introduction:** Hidradenitis suppurativa (HS) is considered to be the most burdensome dermatosis, with a well-documented negative influence on quality of life (QoL). The patient's perception of the disorder, assessed as the self-reported severity, has been used in other dermatoses but not in HS. The aim of this study was to evaluate the usefulness of self-reported HS severity in clinical practice.

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P. K. Krajewski · J. C. Szepietowski (✉)  
Department of Dermatology, Venereology and Allergology, Wrocław Medical University, Chalubinskiego Street 1, 50-368 Wrocław, Poland  
e-mail: jacek.szepietowski@umed.wroc.pl

P. K. Krajewski · S. E. Marrón · Y. Gilaberte-Calzada  
Dermatology Department, University Hospital Miguel Servet, Paseo de Isabel la Católica 1-3, 50009 Zaragoza, Spain

S. E. Marrón · L. Tomas Aragones  
Aragon Psychodermatology Research Group (GAI+PD), Calle San Juan Bosco, 13, 50009 Zaragoza, Spain

L. Tomas Aragones  
Department of Psychology, University of Zaragoza, Calle Pedro Cerbuna, 12, 50009 Zaragoza, Spain

**Methods:** The study was performed on a group of 130 Spanish HS patients. HS severity was assessed for all the subjects. Hurley staging and patient self-reported severity were used. Moreover, QoL impairment was evaluated using the Dermatology Life Quality Index (DLQI) and the Hidradenitis Suppurativa Quality of Life 24 (HSQoL-24) questionnaire.

**Results:** The severity of HS according to the Hurley staging was most commonly assessed as Hurley II (47.7%), indicating moderate disease, followed by severe disease (Hurley III, 26.9%) and mild disease (Hurley I, 25.4%). According to the patient self-reported HS severity, most of the patients reported having mild disease (76 patients, 58.5%), followed by moderate disease (31 patients, 23.8%). Only 23 patients (17.7%) assessed their disease as severe. Moreover, men reported mild disease significantly more frequently than women (70.9% and 49.3%, respectively;  $p = 0.014$ ). The self-reported HS severity correlated positively with the effect of the disease on patient QoL assessed with DLQI ( $r = 0.288$ ,  $p < 0.001$ ). Likewise, a strong positive correlation was found between self-reported HS severity and QoL impairment assessed with HSQoL-24 ( $r = 0.404$ ,  $p = 0.001$ ). No statistically significant correlation between Hurley severity stage and DLQI or HSQoL-24 was found. Moreover, there were significant differences in both DLQI and HSQoL-24 total score between different self-reported HS severities. This was not

seen for any of the QoL instruments or for Hurley severity staging.

**Conclusion:** The results show that self-assessment severity may reflect patients' subjective feelings more adequately than popular objective instruments, and there should be a place for its use in daily clinical practice.

**Keywords:** Hidradenitis suppurativa; Self-reported severity; Hurley; Assessment

### Key Summary Points

Hidradenitis suppurativa (HS) is a chronic inflammatory dermatosis with a well-documented negative influence on quality of life (QoL).

The patient's perception of the disorder, assessed as the self-reported severity, has been used in other dermatoses, but not in HS.

The aim of the study was to assess the clinical usefulness of self-reported HS severity evaluation.

The self-reported severity correlated positively with QoL impairment assessed with the Dermatology Life Quality Index and Hidradenitis Suppurativa Quality of Life 24. Different HS severities had different effects on QoL.

The above-mentioned results were not found for Hurley staging, indicating that self-reported disease severity may more adequately reflect the patient's perspective.

## INTRODUCTION

A patient-reported outcome (PRO) is defined as a type of patient health measurement that comes directly from the patient, without any interpretation of the results by a clinician or others [1]. In recent years, PROs have become

an important part of a new holistic approach to the patient in both clinical and academic settings [1]. These subjective measurements allow physicians to gain an insight into the patient's perspective and to understand the patient's attitudes, burden, and feelings [2]. Dermatological disorders are often associated with disfigurement and a negative influence on the patient's quality of life (QoL), which may not be adequately reflected by an assessment of the area and the severity of the disease [3–5]. Therefore, PROs are an important part of routine dermatological care and scientific research, and are currently commonly used as endpoints in clinical trials [6].

Hidradenitis suppurativa (HS) is a burdensome, debilitating, chronic inflammatory dermatosis for which QoL impairment is well documented [5, 7–9]. The severity of the disease is commonly assessed and evaluated by a clinician using many available instruments [10–12]. The aim of this study was to assess the usefulness of a self-reported hidradenitis suppurativa (HS) severity scale and to evaluate if there is a place for it in routine dermatology practice.

## METHODS

### Study group

The study was performed on a group of hidradenitis suppurativa patients treated at the following hospitals in Spain between 2016 and 2017: University Hospital Miguel Servet (Zaragoza), Royo Villanova Hoospital (Zaragoza), Barbastro Hospital (Huesca), Infanta Sofia Hospital (Madrid), Santa Creu I Sant Pau Hospital (Barcelona), and Doctor Negrin Hospital (Las Palmas de Gran Canaria). All the patients were examined and assessed by a trained specialist in dermatology. Basic sociodemographic data were collected, including gender, age, weight, and height, as well as age at onset of the disease, its duration, and the number of affected areas. The study was conducted according to the guidelines of the Declaration of Helsinki of 1964 and its later amendments. The study was accepted by the Clinical Research Ethics Committee of Aragon

(CEICA) on 10 February 2016 (number PI16/020), and by the corresponding committees in the other participating hospitals. Moreover, a signed consent was obtained for every patient before their inclusion in the study.

### Quality of life

The effect of the disease on the quality of life (QoL) of each patient was assessed using the Dermatology Life Quality Index (DLQI) and the newly developed, HS-specific Hidradenitis Suppurativa Quality of Life 24 (HSQoL-24) questionnaire. DLQI is a widely used, user-friendly, dermatology-specific tool for assessing the impacts of skin diseases on quality of life. It was developed in 1994 by Finlay and Khan [13], and has been used since then for a variety of dermatoses, including psoriasis, atopic dermatitis, and HS [9, 14, 15]. It is a 10-item instrument, and the degree of impairment is assessed on a 4-point scale (0: not at all, 3: very much) for each item within a 7-day recall period. The maximum achievable score is 30 points, and the higher the score, the bigger the impact on QoL. HSQoL-24 is a new Spanish HS-specific questionnaire that was translated into and validated in English in 2021 [16, 17]. It consists of 24 items divided into six life domains. This instrument evaluates the impact on QoL in a 4-week recall period. Each item is scored on a 5-point Likert scale. The maximum achievable score is 96 points [16, 17].

### HS severity

HS severity was assessed for all the subjects. Hurley staging and patient self-reported severity were used. Hurley staging was introduced by Hurley in 1989 [10]. It divides the severity of the disease into three stages from the mildest to the most severe (Hurley I to Hurley III, respectively). Moreover, a self-reported HS severity scale was used, in which patients were asked to evaluate the severity of their disease at the time of clinical evaluation on a verbal rating scale. The subjects were asked to assess their disease severity as mild, moderate, or severe (see Supplementary Table 1).

### Statistical analysis

Statistical analysis of the obtained results was performed with the IBM SPSS Statistics v. 26 (SPSS INC., Chicago, IL, USA) software. All data were assessed for a normal or abnormal distribution. The minimum, maximum, mean, and standard deviation were calculated. Quantitative variables were evaluated using the Mann–Whitney *U* test and Spearman's or Pearson's correlations. For qualitative data, the chi-squared test was used.

Differences in total DLQI and total HSQoL-24 between patients with different severities according to the self-reported severity and the Hurley staging system were assessed via Kruskal–Wallis one-way analysis of variance on ranks. A two-sided *p* with a value lower than 5% was considered significant.

## RESULTS

The group consisted of 130 consecutive HS patients: 75 females (57.7%) and 55 males (42.3%). The patients were  $37.3 \pm 11.9$  years old on average, with no age difference observed between the sexes. The population was characterized as overweight, with a mean BMI of  $29.0 \pm 5.6$  kg/m<sup>2</sup>. Women tended to have a higher BMI than men ( $30.1 \pm 6.0$  kg/m<sup>2</sup> and  $27.5 \pm 4.6$  kg/m<sup>2</sup>, respectively; *p* = 0.023). The mean age at onset of the disease was reported as  $23.1 \pm 10.9$  years old. The disease started significantly earlier in females than in males ( $21.8 \pm 11.2$  years old and  $24.9 \pm 10.5$  years old, respectively; *p* = 0.021). The patients had suffered from HS for  $14.1 \pm 11$  years on average, and the disease affected about  $2.2 \pm 1$  skin areas (Table 1).

According to Hurley staging, the severity of HS in the majority of patients was assessed as Hurley II, indicating moderate disease, followed by severe disease (Hurley III) and mild disease (Hurley I). No differences in Hurley severity assessment between the sexes were found. According to the patient self-reported HS severity, most of the patients reported having mild disease (76 patients, 58.5%), followed by moderate disease (31 patients, 23.8%). Only 23

**Table 1** Patient characteristics

Characteristic	Whole group ( <i>n</i> = 130)	Women ( <i>n</i> = 75)	Men ( <i>n</i> = 55)	<i>P</i>
Sex				
Number of men (%)	55 (42.3)	NA	NA	NA
Number of women (%)	75 (57.7)			
Age				
Mean ± SD (years)	37.3 ± 11.9	37.3 ± 11.9	37.4 ± 11.9	NS
Body mass index (BMI)				
Mean ± SD (kg/m <sup>2</sup> )	29.0 ± 5.6	30.1 ± 6.0	27.5 ± 4.6	0.023
Age at onset of the disease				
Mean ± SD (years old)	23.1 ± 10.9	21.8 ± 11.2	24.9 ± 10.5	0.021
Duration of the disease				
Mean ± SD (years)	14.1 ± 11.0	15.6 ± 11.2	12.1 ± 10.5	
Number of locations				
Mean ± SD	2.2 ± 1.0	2.2 ± 1.0	2.3 ± 1.1	NS

*SD* standard deviation, *NS* not significant, *NA* not applicable, *n* number of participants

patients (17.7%) assessed their disease as severe. Moreover, men reported mild disease significantly more frequently than women ( $p = 0.014$ ). This difference was not observed for other HS severities (Table 2). On average, HS had a moderate effect on the patient's life, with a mean DLQI score of  $8.4 \pm 7.2$  points. The

perceived effect was significantly greater for women than for men ( $p = 0.001$ ). The impairment of QoL assessed with HSQoL-24 was considered to be serious, with a mean global score of  $44.1 \pm 19.2$  points. Similar results were visible for every life domain aside from personal, for which QoL impairment was assessed as

**Table 2** Hidradenitis suppurativa severity

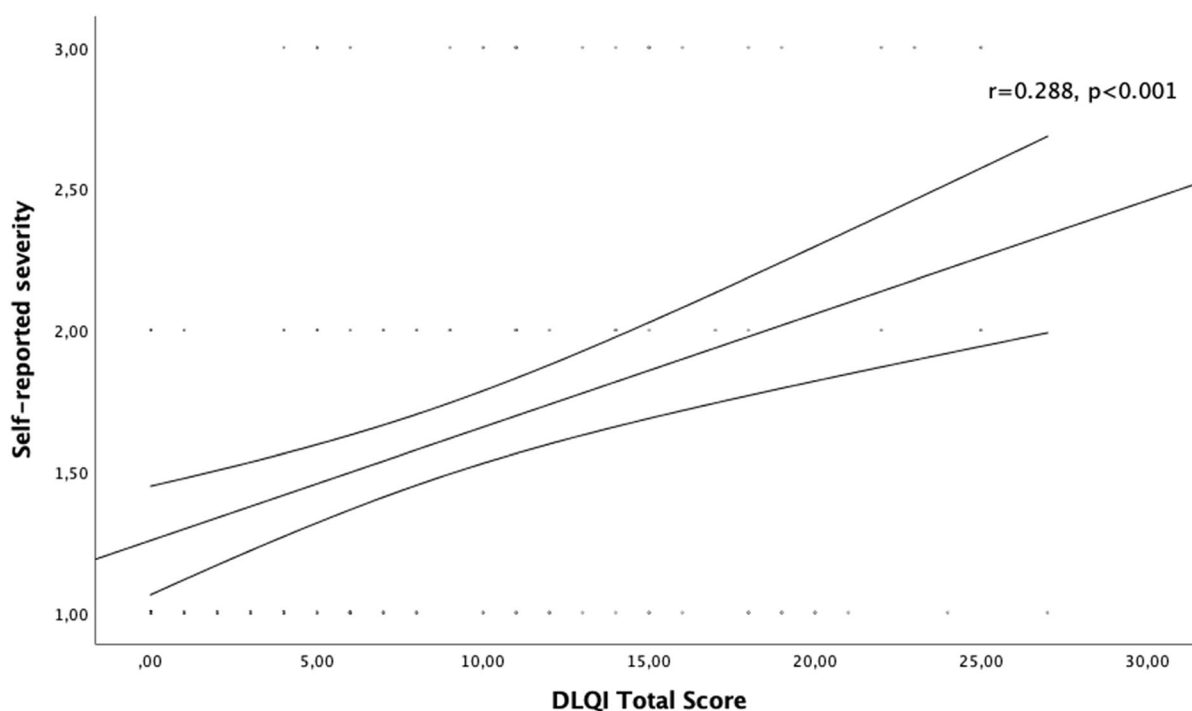
Characteristics	Whole group ( <i>n</i> = 130)	Women ( <i>n</i> = 75)	Men ( <i>n</i> = 55)	<i>P</i>
Hurley stages, number of participants (%)				
I	33 (25.4)	21 (28.0)	12 (21.8)	NS
II	62 (47.7)	31 (41.3)	31 (56.4)	NS
III	35 (26.9)	23 (30.7)	12 (21.8)	
Self-reported HS severity, number of participants (%)				
Mild	76 (58.5)	37 (49.3)	39 (70.9)	0.014
Moderate	31 (23.8)	22 (29.3)	9 (16.4)	NS
Severe	23 (17.7)	16 (21.3)	7 (12.7)	NS

*N* number of participants; *NS* not significant

**Table 3** Quality of life impairment

Characteristic	Whole group ( <i>n</i> = 130)	Women ( <i>n</i> = 75)	Men ( <i>n</i> = 55)	<i>P</i>
DLQI				
Total score (mean ± SD)	8.4 ± 7.2	10.1 ± 7.3	6.1 ± 6.4	0.001
HSQoL-24 (mean ± SD)				
Global	44.1 ± 19.2	49.8 ± 19.4	36.3 ± 16.1	< 0.001
Psychosocial	46.6 ± 21.5	52.9 ± 20.6	38.1 ± 19.8	< 0.001
Economic	39.6 ± 36.8	49.3 ± 38.5	26.4 ± 29.8	0.001
Occupational	45.5 ± 32.4	47.3 ± 33.2	43.1 ± 31.5	NS
Relationships	51.4 ± 31.6	58.9 ± 35.3	41.1 ± 22.2	0.001
Personal	24.9 ± 21.7	28.5 ± 22.3	20.0 ± 19.9	0.026
Clinical	46.8 ± 24.6	50.3 ± 27.3	42.0 ± 19.7	NS

*DLQI* Dermatology Life Quality Index, *HSQoL-24* Hidradenitis Suppurativa Quality of Life 24, *n* number of participants, *SD* standard deviation, *NS* not significant



**Fig. 1** Correlation of self-reported disease severity with DLQI

moderate ( $24.9 \pm 21.7$  points). As also seen for the DLQI, women scored significantly higher for the HSQoL-24 global score ( $p < 0.001$ ), as well as for every life domain excluding the clinical and occupational domains (Table 3).

The self-reported HS severity correlated positively with the effect of the disease on patient QoL as assessed with DLQI ( $r = 0.288$ ,  $p < 0.001$ ) (Fig. 1). Likewise, a strong positive correlation was found between self-reported HS severity and QoL impairment as assessed with HSQoL-24 ( $r = 0.404$ ,  $p = 0.001$ ) (Fig. 2). No statistically significant correlation was found between Hurley severity stage and DLQI or HSQoL-24. Moreover, different self-reported HS severities showed significantly different DLQIs and HSQoL-24 total scores (Figs. 3 and 4). This was not seen for any of the QoL instruments or for Hurley severity staging (Table 4). The kappa value for the agreement between Hurley stage and self-reported severity was 0.153.

## DISCUSSION

Hidradenitis suppurativa (HS) is a chronic, debilitating, recurrent inflammatory skin disorder of unknown pathogenesis that affects the pilosebaceous unit [18]. It is characterized by the formation of deep-seated inflammatory nodules, predominantly in intertriginous locations such as the groin, armpits, and anogenital area [19]. In the course of the disease, nodules progress into abscesses, sinuses, and scarring [19]. The prevalence of the disease has been reported to peak in young adults between 20 and 40 years of age. The exact incidence varies greatly among the available studies, and is currently estimated at 0.03–1% [20, 21]. Due to the resulting continuous purulent discharge, foul smell, and disease-associated pain, HS is considered the most burdensome form of dermatosis, and has a well-documented negative impact on patient QoL. This disease is associated with a high incidence of depression,

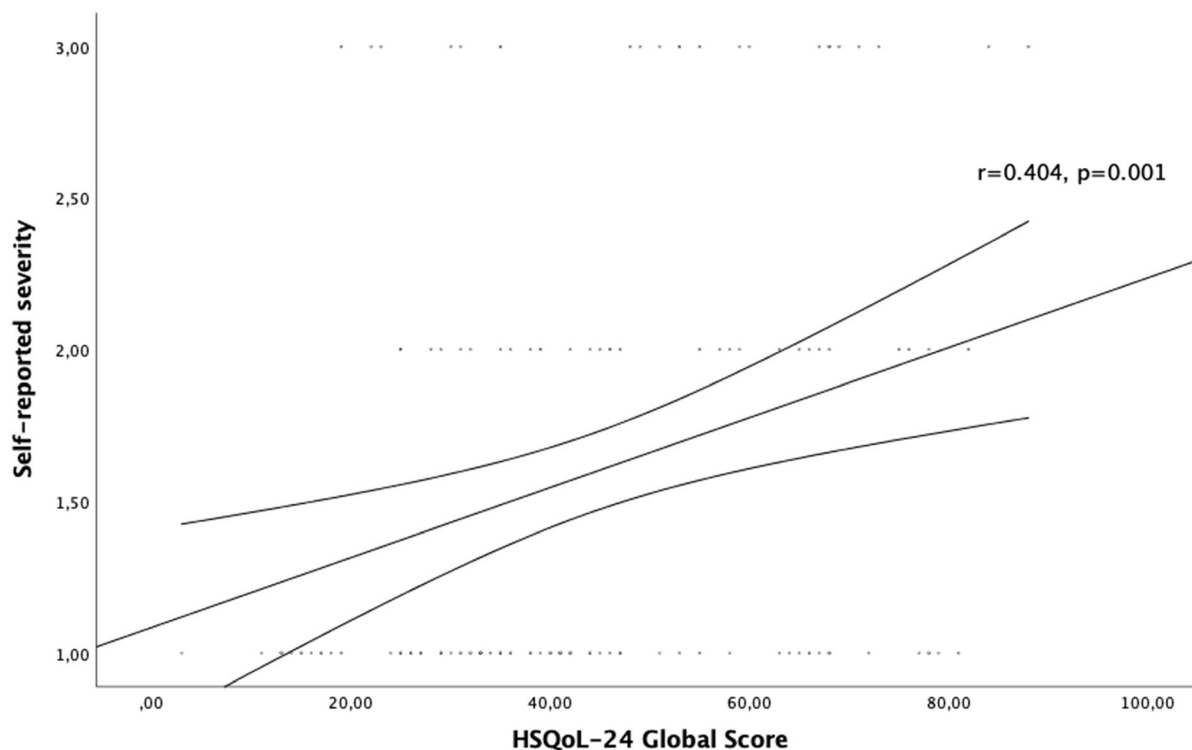
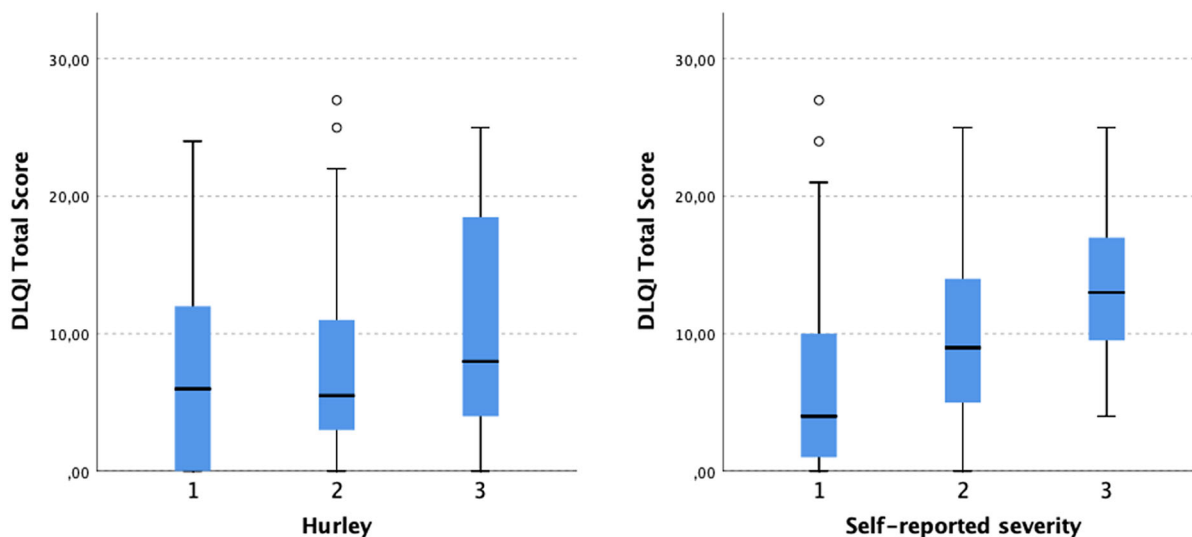
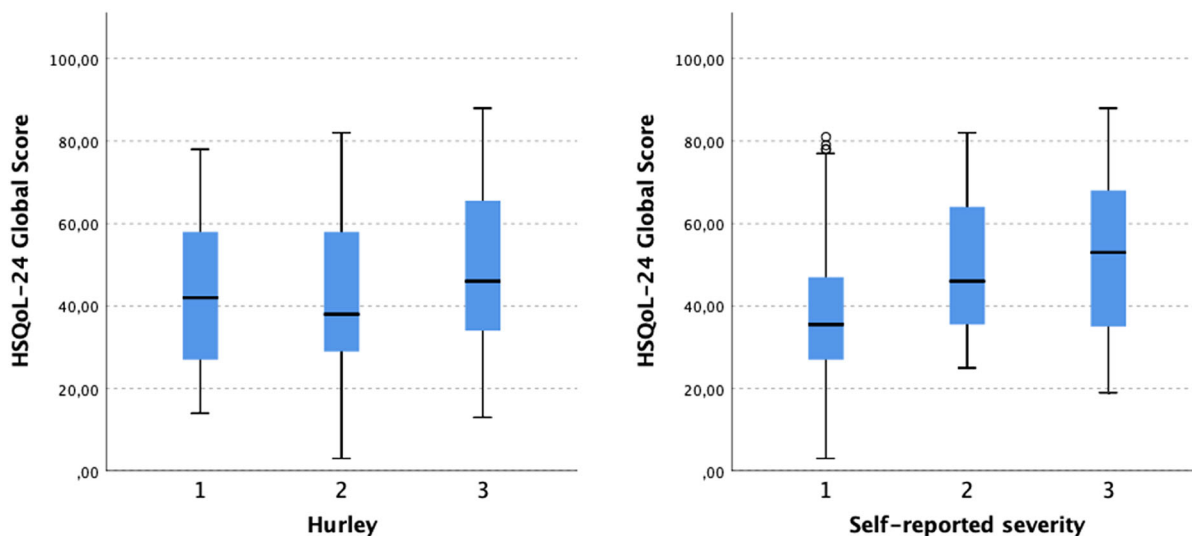


Fig. 2 Correlation of self-reported disease severity with HSQoL-24



**Fig. 3** Differences in DLQI total score between different self-reported HS severities and between different HS severities assessed with Hurley staging



**Fig. 4** Differences in HSQoL-24 global score between different self-reported HS severities and between different HS severities assessed with Hurley staging

anxiety, stigmatization, alexithymia, workplace challenges, and even suicide ideation [22–26]. Moreover, it negatively affects patients’ partners and families [27].

The clinical severity of the disease may be assessed using a variety of instruments. Among

the most frequently used are the Hurley staging system [10], the International Hidradenitis Suppurativa Severity Score (IHS4) [11], the Sartorius score [28], and the Physician Global Assessment (PGA) [29]. It is worth underlining that all of the previously mentioned scoring

**Table 4** Differences in QoL impairment between different HS severities

Severity assessment	DLQI score (mean $\pm$ SD)	<i>p</i>	HSQoL-24 score (mean $\pm$ SD)	<i>p</i>
Hurley				
I	7.6 $\pm$ 7.2		42.8 $\pm$ 18.9	
II	7.4 $\pm$ 6.3	NS	42.6 $\pm$ 19.2	NS
III	10.91 $\pm$ 8.3		47.8 $\pm$ 19.8	
Self-assessed				
Mild	6.4 $\pm$ 6.8		39.4 $\pm$ 18.6	
Moderate	9.7 $\pm$ 6.8	< 0.001	49.1 $\pm$ 17.3	0.005
Severe	13.3 $\pm$ 6.5		52.7 $\pm$ 19.8	

NS not significant, SD standard deviation

systems are objective and are designed to be used by a physician. The patient's perception of the disorder, assessed as the self-reported severity, has been used for other dermatoses. Self-reported AD severity questionnaires include the Patient-Oriented SCORAD (PO-SCORAD) and Self-Administered Eczema Area and Severity Index (SA-EASI) [30, 31]. Similarly to their use in AD, patient-reported outcome measurements (PROMs) are also commonly used in psoriasis. The self-assessed Simplified Psoriasis Index (saSPI) is an instrument that combines the psychosocial impact of psoriasis, its current severity, and past history and interventions [32]. The severity assessment includes the extent of the disease and the choice of sentences that best describe the overall state of psoriasis at the time of examination [32]. The maximum achievable score for the severity of the disease is 50 points, and the higher the result, the more severe the AD. Moreover, it was proven that the results correlate strongly with the Psoriasis Severity and Area Index (PASI) [32]. Regarding HS, to the best of our knowledge, there are only three reports of attempts to use self-reported severity measurements in the literature [33–35]. The first, published by Cusack et al. [34], was performed on a group of 6 patients diagnosed with HS who were treated with etanercept [34]. The patients were supposed to assess the severity of the disease at the beginning and end of the therapy. Moreover, at

the end of the treatment, all patients had to estimate the percentage improvement in HS [34]. In 2015, Deckers et al. [35] tried, for the first time, to determine the capability of patients to self-assess their Hurley stage using pictures. They found that in 76% of the cases, the results were similar to those given by a physician [35]. Moreover, a substantial agreement (with a weighted kappa of 0.63) was achieved, which was comparable to that seen in similar studies of psoriasis and atopic dermatitis [35]. The only available validation of a self-reported severity tool was published in 2019 by Senthilnathan et al. [33]. The tool consisted of 10 color photographs of different Hurley stages which 24 patients were supposed to choose from. The results, although worse than in the previous study, showed moderate agreement between assessments performed by patients and those performed by physicians (a weighted kappa of 0.57), indicating that patients may be able to assess their severity adequately [33].

The above-mentioned results clearly show that self-reported severity is a reliable tool for gaining the patient's perspective and new insight into the disease. Contrary to Hurley staging, self-reported severity correlated positively with QoL impairment. Moreover, differences in QoL impairment between different self-assessed severities of the disease were found. This may indicate that self-reported severity reflects the patient's subjective feelings more



adequately than objective severity measures such as Hurley staging.

We understand that our study has some limitations. Firstly, only Hurley staging was used to assess severity, which may not be the most detailed and reliable measurement. Nevertheless, it is necessary to underline that Hurley staging is still one of the most commonly used HS staging systems worldwide. Secondly, the self-reported severity assessment was not previously validated nor tested on smaller groups.

## CONCLUSION

In conclusion, to the best of our knowledge, this is the first study to assess the usefulness of the self-reported severity of HS. The results of our study show that self-reported severity may be adequate for HS severity assessment and there should be a place for its use in daily clinical practice in the future. Nevertheless, further studies with validated objective tools for the assessment of HS are necessary before introducing this PROM into daily clinical practice.

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**Author Contributions.** All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Servando E Marrón, Lucía Tomas Aragones and Yolanda Gilaberte-

Calzada. The first draft of the manuscript was written by Piotr K Krajewski and Jacek C Szepletowski and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

**Disclosures.** Piotr K Krajewski, Servando E Marrón, Lucía Tomas Aragones, Yolanda Gilaberte-Calzada and Jacek C Szepletowski have nothing to disclose.

**Compliance with Ethics Guidelines.** The study was conducted according to the guidelines of the Declaration of Helsinki of 1964 and its later amendments. The study was accepted by the Clinical Research Ethic Committee of Aragon (CEICA) on 10 February 2016 (number PI16/020), by the corresponding committees in the other participants hospitals. Moreover, a signed consent was obtained for every patient, before including in the study.

**Data Availability.** The data that support the findings of this study are available from the corresponding author on reasonable request and with permission of all the authors. The data are not publicly available due to reasons of sensitivity and other reasons

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