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# Physical symptoms and psychosocial problems associated with hidradenitis suppurativa: correlation with Hurley stage

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## Abstract

**Background:** Quality of life (QOL) in hidradenitis suppurativa (HS) patients is negatively impacted by physical and psychosocial problems. The aim of this study was to investigate the frequency and severity of HS-specific symptoms and to correlate these with disease severity.

**Methods:** We analyzed medical record data from 145 patients seen in an academic HS specialty clinic between August 2009 to March 2018.

**Results:** Hurley stage III patients had significantly higher mean Dermatology Life Quality Index (DLQI) scores (20.2) compared to patients with Hurley stage I (11.3) and II (13.9), ( $P < 0.001$  and  $P = 0.001$ , respectively). More than 75% of patients reported physical symptoms of drainage, irritation, pain, itching, bleeding, and odor. There were associated psychosocial problems of embarrassment and self-consciousness. Symptom severity was most strongly correlated with disease severity for odor (correlation coefficient 0.4,  $P < 0.001$ ), difficulty moving arms (0.323,  $P < 0.001$ ), negative impact on job/school (0.303,  $P < 0.001$ ), and negative impact on relationships (0.298,  $P < 0.001$ ).

**Conclusion:** Our results highlight the significant burden of HS and the need for a more comprehensive, HS-specific evaluation tool to better assess the QOL of this patient population.

**Limitations:** A small cohort in a single academic center.

## Introduction

Hidradenitis suppurativa (HS) is a chronic, often debilitating disease characterized by recurrent, painful subcutaneous nodules and draining sinus tracts. Its prevalence has been estimated to be 0.1% in the United States [1]. Symptoms associated with HS can greatly impair physical, mental, and social aspects of patients' lives. Hidradenitis suppurativa has been found to impart greater quality of life (QOL) burden than other chronic dermatologic conditions including psoriasis, atopic dermatitis, and chronic urticaria [2,3]. Previous studies have found that HS patients have twice the rate of suicide compared to the general population [4] and up to one fifth have major depression [5].

Pain is the most common symptom associated with HS [6,7], but patients report experiencing many other symptoms that negatively impact their QOL. Thus, there is a need for a comprehensive HS-specific QOL measure. This study investigates several physical symptoms and psychosocial problems of HS in addition to pain and correlates their severity with Hurley stages.

## Methods

A retrospective data analysis was conducted on 145 patients who presented to the University of California, Los Angeles (UCLA) HS clinic between August 2009 to March 2018 and who completed

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both the Dermatology Life Quality Index (DLQI) and a numeric rating scale (NRS, 0-10) of severity of several HS-related physical symptoms and psychosocial problems. Patient characteristics and study variables were summarized using mean (range) or n (%) unless otherwise noted. We compared DLQI between groups (e.g. gender, race) using t-tests. To investigate if significant associations held after controlling for Hurley stage, we used linear regression. We assessed associations between study variables (e.g. Hurley stage of each patient and symptom disease severity) using the Spearman correlation. P-values <0.05 were considered statistically significant. All analyses were run using SPSS V25 (IBM Corp. Armonk, NY). This study was approved by the UCLA Institutional review board (IRB#17-001267).

## Results

In our cohort of 145 patients, 64.8% were women and 35.2% were men. The mean age at presentation was 32.7 years (range 15 to 65) and 15.9% were Hurley I, 49.7% were Hurley II, and 17.9% were Hurley III. Other patient characteristics are summarized in **Table 1**. The mean DLQI score was 14.2 (range 0-30); a score above 11 means the disease has a very large effect on patient's life [8]. Hurley stage III patients had significantly higher mean DLQI scores (20.2) compared to Hurley stages I (11.3) and II (13.9), (P<0.001 and P=0.001, respectively). After controlling for Hurley stage, mean DLQI did not significantly differ based on gender (women versus men), race (non-white versus white), weight (obese, or BMI ≥30, versus non-obese), and functional status (disabled versus non-disabled).

### Reported HS physical symptoms and psychosocial problems

Regarding HS-related symptoms, the majority of the patients reported drainage (91.7%), irritation (90.3%), pain (86.2%), itching (82.1%), bleeding (84.8%), odor (77.2%), burning (62.1%), and increased sweating (55.9%). The majority of patients also reported psychosocial problems such as embarrassment (86.2%), self-consciousness (85.5%), disability (72.4%), depression (66.2%), difficulty

**Table 1.** Patient characteristics.

Characteristic	
Gender – n (%)	
Women	94 (64.8%)
Men	51 (35.2%)
Age at presentation to UCLA HS Clinic – mean (range)	32.7 (15-65)
Age at onset of HS – mean (range) <sup>1</sup>	21.9 (6-63.5)
Race/Ethnicity – n (%)	
White	40 (27.6%)
Hispanic	24 (16.6%)
Bi- or multi- racial	23 (15.9%)
Black	20 (13.8%)
Middle Eastern	12 (8.3%)
Asian	10 (6.9%)
Indian Asian	7 (4.8%)
Native American	3 (2.1%)
Other/Unknown	6 (4.1%)
Occupation <sup>2</sup>	
Employed	83 (57.2%)
Disabled	8 (5.5%)
Student	39 (2.7%)
Homemaker	2 (1.4%)
Retired	3 (2.1%)
BMI at Presentation to UCLA HS Clinic <sup>3</sup> – mean (range)	30.1 (19-60)
Hurley Stage – n (%)	
Stage I	47 (32.4%)
Stage II	72 (49.7%)
Stage III	26 (17.9%)
DLQI mean (Q1-Q3) <sup>4</sup>	
Hurley Stage I	11.3 (5-19)
Hurley Stage II	13.9 (8.8-21)
Hurley Stage III	20.2 (13-27)

<sup>1</sup>Missing- 6; <sup>2</sup>Missing- 10; <sup>3</sup>Missing- 8; <sup>4</sup>Missing- 20

shaving (59.3%), reclusiveness (59.3%), difficulty moving their arms (53.8%), and a negative impact on job/school performance (51.3%), (**Table 2**).

### Symptoms by Hurley stage

Compared to Hurley stage I patients, Hurley stage III patients reported higher rates of negative impact on relationships (+42.9%), negative impact on job/school (+38.6%), difficulty moving arms (+35.2%), odor (+34.9%), and feeling depressed (+28.9%), (**Figure 1**). Mean symptom severity ratings

**Table 2.** *Hidradenitis suppurativa physical symptom and psychosocial problem scores.*

HS Physical Symptoms	Symptom Present n (%)	Mean Severity Score (1-10) ± SD	Correlation with Hurley Stage	P-Value
Irritation	131 (90.3%)	6.76 ± 3.09	0.157	0.059
Drainage	133 (91.7%)	6.14 ± 3.12	0.259	0.002*
Pain	125 (86.2%)	6.01 ± 3.18	0.145	0.083
Itching	119 (82.1%)	5.03 ± 3.45	0.165	0.048*
Bleeding	123 (84.8%)	4.95 ± 3.25	0.250	0.002*
Odor	112 (77.2%)	4.65 ± 3.59	0.400	<0.001*
Burning	90 (62.1%)	3.84 ± 3.74	0.237	0.004*
Increased Sweating	81 (55.9%)	3.32 ± 3.56	0.157	0.059
HS Psychosocial Problems				
Self-Conscious	124 (85.5%)	6.26 ± 3.54	0.230	0.005*
Embarrassed	125 (86.2%)	5.95 ± 3.56	0.252	0.002*
Disability	105 (72.4%)	5.41 ± 3.96	0.171	0.039*
Depressed	96 (66.2%)	4.09 ± 3.80	0.241	0.004*
Difficulty Shaving	86 (59.3%)	4.08 ± 3.98	0.134	0.107
Reclusive	86 (59.3%)	3.80 ± 3.80	0.195	0.018*
Difficulty Moving Arms	78 (53.8%)	3.79 ± 4.02	0.323	<0.001*
Difficulty Sitting	68 (46.9%)	3.40 ± 4.08	0.079	0.342
Negative Impact on Job/School	77 (53.1%)	3.30 ± 3.78	0.303	<0.001*
Negative Impact on Relationships	67 (46.2%)	3.13 ± 3.96	0.298	<0.001*
Financial Hardship	35 (24.1%)	1.53 ± 3.11	0.181	0.029*

\*P&lt;0.05

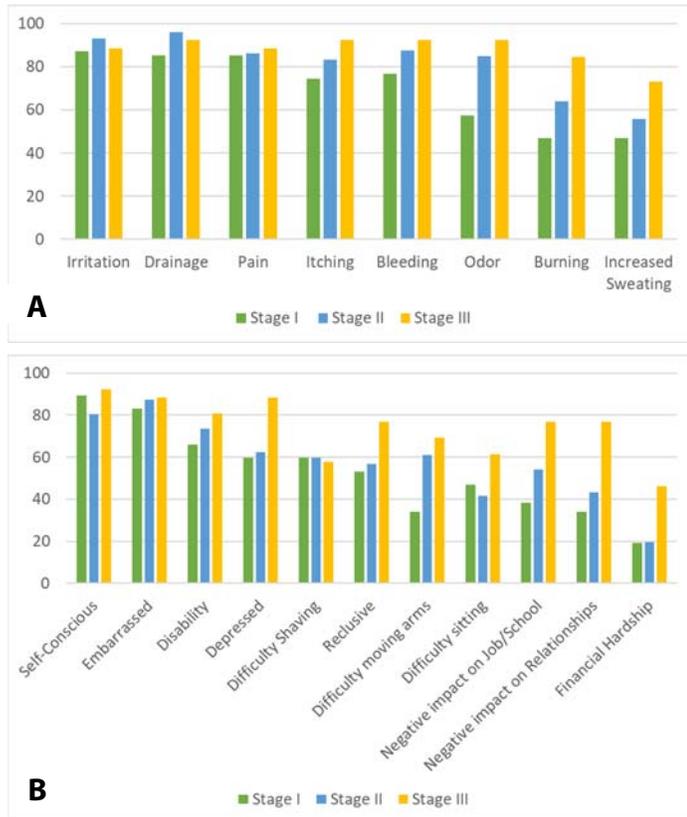
were significantly correlated with increasing disease severity (**Figure 2**), with the strongest correlations for odor (correlation coefficient 0.4, P<0.001), difficulty moving arms (0.323, P<0.001), negative impact on job/school (0.303, P<0.001), and negative impact on relationships (0.298, P<0.001), (**Table 2**). There was a trend for mean pain severity score to be correlated with increasing Hurley stage (Hurley I- 5.46, II- 6.19, III- 6.50, P=0.083).

## Discussion

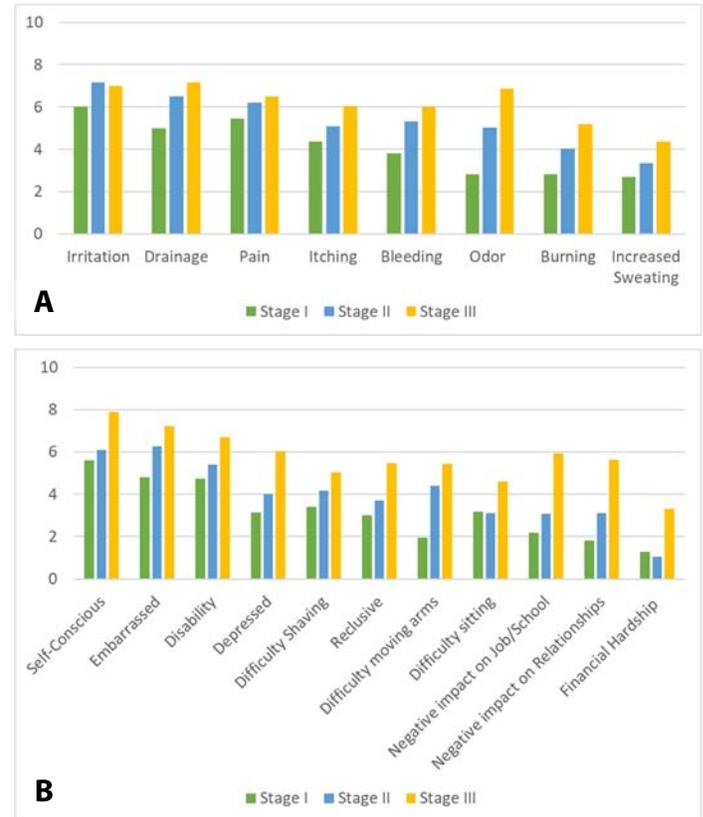
Most patients in our study reported a broad range of HS symptoms, with more than 75% of patients reporting irritation, drainage, pain, itching, bleeding, odor, self-consciousness, and embarrassment. The results of this study parallel findings from a recent multinational survey of HS patients in which drainage, odor, and pruritus were commonly documented [9]. These symptoms are important to consider in the assessment of QOL in patients with

HS and are not adequately captured in current QOL questionnaires used in clinics. In an international Delphi process aimed to define a core outcome set for HS clinical trials, patients and health care professionals ranked pain so highly that it was nominated to form its own domain among the five core domains, which include pain, physical signs, HS specific quality of life, global assessment, and progression of course [10]. Patients strongly supported “symptoms” as a sixth domain, which would contain items such as drainage and fatigue, but there was insufficient support from health care professionals to reach threshold consensus that “symptoms” be considered its own domain [10].

In our study, pain had a high rating across Hurley stages. However, irritation, self-consciousness, drainage, embarrassment, disability, and itching had severity scores similar to pain. Thus, the impact of other symptoms on patients’ lives should be taken into account. For example, malodorous drainage



**Figure 1. A) Physical symptom frequency (%) by Hurley stage. B) Psychosocial problem frequency (%) by Hurley stage.**



**Figure 2. A) Mean physical symptom severity by Hurley stage. B) Mean psychosocial problem severity by Hurley stage.**

may significantly impact patients’ social and emotional functioning [11] and restrict daily decisions such as wardrobe choices. Tailoring treatment regimens and wound care options to address these specific additional HS symptoms would likely improve patient QOL.

A majority of our HS patients reported symptoms of drainage, irritation, bleeding, odor, and increased sweating, which are not assessed by the DLQI. Efforts are ongoing to develop a validated HS specific QOL measure that can be used in clinics. The HiSQOL is a recently validated tool for the measurement of QOL in clinical trials [12]. This measure includes three categories: symptoms, psychosocial parameters, and activities-adaptions. Items assessed in our study that are not included in HiSQOL but may be helpful for physicians to consider in a clinical visit include irritation, bleeding, burning, increased sweating, disability, reclusiveness, difficulty moving arms, difficulty sitting, and difficulty shaving.

Limitations of this study are that it was carried out at a single academic center with a small cohort size.

## Conclusion

Our results demonstrate the broad impact of HS on QOL and supports the need for a comprehensive HS-specific QOL assessment questionnaire tool to accurately capture the physical functioning and psychosocial well-being of these patients.

## Potential conflicts of interest

Vivian Shi is a stock shareholder of Learn Health, and has served as an advisor, investigator and/or speaker for Sanofi, Regeneron, AbbVie, Novartis, Pfizer, Leo, Dermira, Eli Lilly, SUN Pharma, Menlo Therapeutics, GpSkin, Burt’s Bees and Skin Actives Scientific. Jennifer Hsiao has served as an advisor for Novartis. There were no financial incentives or transactions

otherwise relevant to this manuscript. Shanice McKenzie, Christina Harview, Allison Truong, Tristan Grogan, and Richard Bennett have no potential conflicts of interest to declare.

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