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## Dermatology Online Journal

### Title

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### Permalink

<https://escholarship.org/uc/item/78875435>

### Journal

Dermatology Online Journal, 30(3)

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### Publication Date

2024

### DOI

10.5070/D330363875

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Peer reviewed

# Sensitive detection of quality of life impact with a hidradenitis suppurativa specific measure

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*Keywords: hidradenitis suppurativa, psychosocial, quality of life*

To the Editor:

Hidradenitis suppurativa (HS) markedly impacts quality of life (QOL) even in patients with objectively limited disease [1,2]. However, the generic skin disease QOL tools that have been used to assess the QOL impact of HS may omit important HS symptoms. The Hidradenitis Suppurativa Quality of Life (HiSQOL) survey is a 17-part questionnaire that covers the core HS outcomes: psychological functioning, physical functioning, psychosocial function, ability to work or study, and emotional well-being [3,4]. The HiSQOL may provide useful information on HS specific impact on QOL not captured by generic QOL measures [1,5]. Disease-specific QOL survey tools may allow providers to recognize and better inform clinical interventions to decrease HS disease burden. We assessed how HiSQOL reflected disease specific outcomes on QOL in HS patients.

A total of 153 subjects diagnosed clinically with HS (ICD10 code: L 73.2) at the Wake Forest Baptist Health Dermatology clinics were recruited to complete a survey through mail (N=123) or clinic (N=30), [1]; 90% of responses from clinic and 32.5% of responses from mail were received, completed, and analyzed. Objective HS severity was assessed using a validated HS self-assessment tool [4]. Respondents also self-reported the number of painful nodules, severity of scarring, regions involved, and frequency of leakage and burning associated with their HS. Respondents

completed the HiSQOL and the relationship between disease severity and QOL was assessed. Data were analyzed using the SAS Software 9.4. Differences in group comparisons by mean score were analyzed with analysis of variance (ANOVA) and student t-test. The study was approved by the Institutional Review Board at Wake Forest Baptist Health (IRB00049730).

Demographics of respondents (mean age 39, 90% female, 57% African American) were comparable to non-respondents (mean age 36, 80% female, 38% African American). Hidradenitis suppurativa patients with more severe disease, >5 painful nodules, more severe scarring, daily leakage of fluid, and more frequent burning sensation from lesions had higher HiSQOL scores compared to those with less severe disease (**Table 1**). Objective HS severity was positively correlated to HiSQOL subscores of pain, drainage, itch, odor, depression, embarrassment, anxiety, concentration, along with problems related to walking, exercising, washing oneself, getting dressed, deciding what to wear to avoid discomfort that influence your ability to work and study, sleep, desire or have sexual activity (including pain or fear of pain), (**Table 1**).

Hidradenitis suppurativa is a debilitating disease and even patients with mild disease experience a large impact on QOL [1]. Generic skin disease QOL tools are

**Table 1.** Average, total, individual, and subsection Hidradenitis Suppurativa Quality of Life (HiSQOL) score for each stratified symptom parameter.

Mean scores	Disease severity per Hurley score			Number of body regions with HS		Number of painful nodules		Severity of scarring associated with HS			Frequency of itch associated with HS		Frequency of leakage associated with HS		Frequency of burning associated with HS	
	0 & 1	2	3	<3	≥3	≤5	>5	None to mild	Moderate	Severe	Daily	<Daily	Daily	<Daily	≤1-2/ month	≥1-2/ week
<b>Sum HiSQOL</b>	<b>23.1*</b>	<b>24.7*</b>	<b>35.8*</b>	<b>25.5</b>	<b>30.6</b>	<b>23.3**</b>	<b>35.3**</b>	<b>16.7**</b>	<b>25.0**</b>	<b>37.4**</b>	<b>17.0</b>	<b>38.6</b>	<b>19.4</b>	<b>37.6</b>	<b>18.8***</b>	<b>38.7***</b>
Pain	2.4	2.0	2.8	2.3	2.5	2.1**	2.9**	1.6**	2.3**	2.9	1.6*	3.1*	1.8***	3.1***	1.9***	3.1***
Drainage	1.1***	1.9***	2.9***	2.0	2.2	1.7**	2.6**	0.8**	2.1**	2.7**	1.3***	2.9***	1.3***	3.1***	1.5	3.0
Itch	2	1.7	2.4	2.1	1.9	1.7**	2.5**	1.9	1.8	2.3	1.0***	2.9***	1.7	2.4	1.4***	2.8***
Odor	0.9**	1.6**	1.6**	1.5	2.1	1.5	2.1	0.6**	1.8**	2.4**	0.8***	2.6***	1.0***	2.7***	1.3**	2.4**
<b>Symptoms subscore</b>	<b>5.0**</b>	<b>7.9**</b>	<b>10.2**</b>	<b>7.9</b>	<b>8.7</b>	<b>7.0**</b>	<b>10.1**</b>	<b>5.0**</b>	<b>7.9**</b>	<b>10.2**</b>	<b>4.7***</b>	<b>11.5***</b>	<b>5.8***</b>	<b>11.3***</b>	<b>6.4***</b>	<b>11.2***</b>
Down or depressed	1.1	1.1	1.7	1.0	1.5	1.0*	1.7*	0.6*	1.1*	1.8*	0.8*	1.7*	0.6***	2.0***	0.7***	2.0***
Embarrassed	1.6	1.5	1.9	1.7	1.5	1.5	1.8	0.8**	0.8**	2.0**	0.8***	2.3***	1.1**	2.2**	0.8***	2.4***
Anxious or nervous	0.9**	0.7**	2.0**	1	1.4	0.7**	1.9**	0.6	1.3	1.4	0.7**	1.7**	0.5***	1.9***	0.6***	1.9***
Concentration	0.9	1	1.4	0.9	1.4	0.9	1.5	0.5	1.0	1.6	0.6**	1.6**	0.7**	1.6**	0.7**	1.6**
Affected your desire for sexual activities	2.1	2.0	1.8	1.9	2.1	1.7	2.3	1.5	1.6	2.4	1.0***	2.7***	1.5*	2.4*	1.3**	2.6**
<b>Psychosocial subscore</b>	<b>4.7</b>	<b>6.4</b>	<b>9.2</b>	<b>6.5</b>	<b>7.8</b>	<b>5.8**</b>	<b>9.1**</b>	<b>4.7</b>	<b>6.4</b>	<b>9.2</b>	<b>3.9***</b>	<b>9.9***</b>	<b>4.5***</b>	<b>9.9***</b>	<b>4.3***</b>	<b>10.3***</b>
Walking	0.7	1.1	1.7	0.9**	1.6**	1.0*	1.7*	0.5**	1.1**	1.8**	0.7***	1.8***	0.9**	1.6**	0.8**	1.8**
Exercising	1.3**	1.8**	2.9**	1.8	2.3	1.7**	2.6**	0.8**	2.0**	2.7**	1.5**	2.6**	1.2***	3.0***	1.6**	2.7**
Sleeping	1.1	1.5	1.9	1.4	1.7	1.4	1.8	0.7**	1.4**	2.1**	0.9***	2.1***	1.0**	2.1**	1.4	1.9
Washing yourself	1	1.0	1.8	1.1	1.5	1*	1.7*	0.6**	1.0**	2.0**	0.6***	1.9***	0.8**	1.8**	0.8***	1.9***
Getting dressed	0.8	1.0	1.7	1.1	1.5	0.9**	1.7**	0.8**	0.8**	2.0**	0.6***	1.8***	0.7***	1.8***	0.9**	1.6**
What you wear to avoid discomfort	2.6	2.5	1.9	2.6	2.7	2.5	2.0	2.5	2.6	1.9	2.0*	3.1*	2.0***	3.3***	2.1	3.2
Influenced your ability to work or study	0.7	0.9	1.5	0.9	1.3	0.7**	1.6**	0.4**	0.7**	1.8**	0.6**	1.5**	0.4***	1.8***	0.3***	2***
Made sexual activity difficult due to pain or fear of pain	1.9	1.6	1.7	1.4	1.9	1.4	2.0	0.6**	1.0**	2.0**	0.9**	2.3**	1.3	2.1	1.0**	2.3**
<b>Activities and adaptations subscore</b>	<b>7.5</b>	<b>10.9</b>	<b>16.7</b>	<b>11.1</b>	<b>14.3</b>	<b>10.7**</b>	<b>15.1**</b>	<b>7.5***</b>	<b>10.9***</b>	<b>16.7***</b>	<b>7.8***</b>	<b>17.0***</b>	<b>8.1***</b>	<b>17.5***</b>	<b>9.1***</b>	<b>17.7***</b>

\*, P<0.05; \*\*, P<0.01; \*\*\*, P<0.001.

not sufficiently sensitive to detect differences in QOL between objectively mild versus severe HS. In our cohort, HS had a large impact on patients' QOL. Using an HS-specific QOL measures, respondents with more severe disease, more painful nodules, severe scarring, and more frequent leakage of fluid, itch, and burning experienced worse QOL compared to respondents with less severe symptoms.

The HiSQOL was created based on qualitative research with HS patients from multiple countries to ensure the relevance of the topics in the survey [4]. Specifically, the HiSQOL assesses topics such as drainage, odor, depression, anxiety, concentration, walking, sleeping, washing oneself, and getting dressed, that are not otherwise covered in other generic skin-related QOL survey tools. The HiSQOL may allow for a more detailed understanding of the impact of HS than can be achieved with more generic measures of skin-related QOL [4].

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## Potential conflicts of interest

Steven Feldman has received research, speaking and/or consulting support from a variety of companies including Galderma, GSK/Stiefel, Almirall, Leo Pharma, Baxter, Boehringer Ingelheim, Mylan, Celgene, Pfizer, Valeant, Taro, Abbvie, Cosmederm, Anacor, Astellas, Janssen, Lilly, Merck, Merz, Novartis, Regeneron, Sanofi, Novan, Parion, Quriert, National Biological Corporation, Caremark, Advance Medical, Sun Pharma, Suncare Research, Informa, UpToDate and National Psoriasis Foundation. He is founder and majority owner of [www.DrScore.com](http://www.DrScore.com) and founder and part owner of Causa Research, a company dedicated to enhancing patients' adherence to treatment. Rita Pichardo worked as an advisor for Novartis. Katherine Kelly, Rohan Singh, and Aditi Senthilnathan have no conflicts of interest to disclose.