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Table S1. Characteristics among participants with self-diagnosed hidradenitis suppurativa

	Total (n = 400)
Age, Mean (SD), Years	46.5 (13.2)
Gender, n (%)	
Female	130 (32.5)
Male	270 (67.5)
BMI, Mean (SD), kg/m ²	23.4 (4.6)
BMI, Median [IQR], kg/m ²	22.5 [20.2, 25.4]
BMI, n (%)	
Underweight	35 (8.8)
Normal Weight	252 (63.0)
Overweight	78 (19.5)
Obese	35 (8.8)
Smoking Status, n (%)	
Current Smoker	132 (33.2)
Former Smoker	124 (31.2)
Never Smoker	142 (35.7)
Hours of Sedentary Behavior during Normal Daily Activities, Mean (SD), Hours	7.0 (3.2)
Hours of Sedentary Behavior during Working Hours, Mean (SD), Hours	5.9 (3.3)
Age at Skin Symptom Onset, Mean (SD), Years	32.8 (17.8)
Duration of Skin Symptoms, Mean (SD), Years	13.7 (14.4)
Duration of Skin Symptoms, Median [IQR], Years	8.0 [2.0, 22.3]
Duration of Skin Symptoms, n (%)	
<10 Years	209 (52.2)
10+ Years	191 (47.8)
Body Region Affected by HS Symptom, n (%)	

Head	144 (36.0)
Chest	110 (27.5)
Axillae	169 (42.2)
Abdomen	131 (32.8)
Back	164 (41.0)
Gluteal Region	184 (46.0)
Hip-joint and Groin	137 (34.2)
Around Pubic Region and Anus	76 (19.0)
Other Area(s)	37 (9.2)
HSSA, Mean (SD), Points	33.4 (20.2)
PGIS, n (%)	
Not Present	33 (8.2)
Very Mild	67 (16.8)
Mild	108 (27.0)
Moderate	111 (27.8)
Moderately Severe	62 (15.5)
Severe	13 (3.2)
Extremely Severe	6 (1.5)
Analgesics Use, n (%)	139 (34.8)
Frequency of Analgesics Use, n (%)	
Every Day	28 (20.1)
About 3-6 Times a Week	44 (31.7)
About 1-2 Times a Week	38 (27.3)
About 1-3 Times a Month	18 (12.9)
Less than Once a Month	11 (7.9)
Duration of Analgesics Use, Mean (SD), Years	8.0 (10.7)
Family History of HS, n (%)	
Yes	70 (17.5)
No	249 (62.3)
Prefer Not to Answer / Do Not Know	81 (20.2)

Abbreviations: BMI, body mass index; HS, hidradenitis suppurativa; HSSA, hidradenitis suppurativa symptom assessment; IQR, interquartile range; PGIS, patient global impression of severity; SD, standard deviation.

Table SII. Health-related information among participants with self-diagnosed hidradenitis suppurativa

	Total (n = 400)
Had at Least One Comorbidity, n (%)	226 (56.5)
Types of Comorbidity, n (%)	
Diabetes	30 (7.5)
Hypertension	68 (17.0)
Chronic Kidney Disease	12 (3.0)
Asthma	37 (9.2)
Pneumonia	7 (1.8)
Fatty Liver	15 (3.8)
Dyslipidemia	30 (7.5)
Cerebrovascular Disease	13 (3.2)
Ischemic Heart Disease	5 (1.2)
Cancer	9 (2.2)
Schizophrenia	9 (2.2)
Depression	35 (8.8)
Ulcerative Colitis	3 (0.8)
Crohn's Disease	3 (0.8)
Hirsutism	5 (1.2)
Other Comorbidities	57 (14.2)
History of Physician Diagnosis of Skin Symptoms, n (%)	138 (34.5)
Types of Skin Symptoms, n (%)	
Atopic Dermatitis	66 (47.8)
Miliaria	37 (26.8)
Psoriasis	18 (13.0)
Urticaria	31 (22.5)
Insect Bites	20 (14.5)
Impetigo Contagiosa	12 (8.7)
Shingles	13 (9.4)
Pyoderma Gangrenosum	1 (0.7)

Chronic Pyoderma	2 (1.4)
Folliculitis	5 (3.6)
Boil	12 (8.7)
Carbuncle	3 (2.2)
Atheroma	9 (6.5)
Acne	22 (15.9)
Other Skin Conditions	16 (11.6)

Table SIII. Dermatology life quality index among participants with self-diagnosed hidradenitis suppurativa

	Total (n = 400)
DLQI Total, Mean (SD), Points	9.9 (7.4)
DLQI Domain Scores, Mean (SD), Points	
Symptoms and Feelings	2.9 (1.6)
Daily Activities	2.0 (1.7)
Leisure	1.7 (1.7)
Work and School	1.2 (1.2)
Personal Relationships	1.3 (1.6)
Treatment	0.8 (0.9)

Participants were categorized into 5 groups based on their DLQI total scores: (i) 0-1 points indicated no effect at all, (ii) 2-5 points indicated a small effect, (iii) 6-10 points indicated a moderate effect, (iv) 11-20 points indicated a very large effect, and (v) 21-30 points indicated an extremely large effect on the patient's quality of life.

Abbreviations: DLQI, dermatology life quality index; SD, standard deviation.

Table SIV. Associations of high dermatology life quality index scores with participant characteristics among participants with self-diagnosed hidradenitis suppurativa

	Model 1	Model 2	
	OR (95% CI)	AOR (95% CI)	VIF
Age (Years)	0.97 (0.96, 0.99)	0.97 (0.95, 0.99)	1.22
Male (Ref. Female)	1.37 (0.90, 2.09)	1.26 (0.69, 2.31)	1.13
Clinical Signs on Head (Ref. No Clinical Sign)	1.05 (0.69, 1.59)		
Clinical Signs on Chest (Ref. No Clinical Sign)	1.09 (0.70, 1.71)		
Clinical Signs on Axillae (Ref. No Clinical Sign)	1.40 (0.94, 2.10)		
Clinical Signs on Abdomen (Ref. No Clinical Sign)	1.11 (0.73, 1.70)		
Clinical Signs on Back (Ref. No Clinical Sign)	0.92 (0.61, 1.38)		
Clinical Signs on Gluteal Region (Ref. No Clinical Sign)	0.37 (0.24, 0.56)	0.27 (0.15, 0.48)	1.13
Clinical Signs on Hip-joint and Groin (Ref. No Clinical Sign)	0.62 (0.40, 0.95)		
Clinical Signs around the Pubic Region and Anus (Ref. No Clinical Sign)	1.10 (0.66, 1.82)		
Duration of Skin Symptoms (Years)	1.00 (1.00, 1.03)		
PGIS - Severe (Ref. Non-severe)	2.11 (1.74, 2.57)	2.05 (1.56, 2.69)	1.26
Sub-score of HSSA regarding Pain (Points)	1.57 (1.42, 1.74)		
Sub-score of HiSQOL regarding Pain (Points)	4.61 (3.41, 6.24)	3.35 (2.44, 4.59)	1.03
Visiting Dermatological Department for Skin Symptoms (Ref. No Visit)	1.43 (0.88, 2.31)		
Antibacterial Ointment Use (Ref. No Use)	1.78 (1.17, 2.72)		
Acne Ointment Use (Ref. No Use)	2.68 (1.48, 4.82)		

Oral Antibiotics Use (Ref. No Use)	4.46 (2.39, 8.30)
Oral Antiinflammation Use (Ref. No Use)	3.32 (2.00, 5.51)
Etretinate Use (Ref. No Use)	5.77 (1.58, 21.02)
Injection of Biologics Use (Ref. No Use)	7.85 (1.70, 36.31)
Surgery and/or Surgical Treatment (Ref. No Surgery and/or Surgical Treatment)	2.77 (0.91, 8.43)
Over-the-counter Medication Use (Ref. No Use)	0.54 (0.31, 0.94)

The associations between high DLQI scores and patient characteristics were examined using logistic regression analyses. The dependent variables were the total DLQI scores. The total DLQI scores were categorized into “high DLQI scores” if the total DLQI scores indicated very or extremely large effects on a patient’s quality of life (the DLQI total scores ≥ 11) or “non-high DLQI scores” if the total DLQI scores indicated moderate, small, or no effect at all on a patient’s quality of life (the DLQI total scores < 11). PGIS was categorized into “Non-severe” if participants answered “None”, “Very mild”, “Mild”, or “Moderate”, whereas PGIS was categorized into “Severe” if participants answered “Moderately severe”, “Severe”, or “Extremely severe.” Model 1 was an unadjusted model. Model 2 included demographic variables (age and gender) and variables which were significantly associated with high DLQI scores in Model 1, except for medication use. No multicollinearity was identified in Model 2. Abbreviations: AOR, adjusted odds ratio; CI, confidence interval; DLQI, dermatology life quality index; SD, standard deviation; HiSQOL, hidradenitis suppurativa quality of life; HSSA, hidradenitis suppurativa symptom assessment; OR, odds ratio; Ref, reference; VIF, variance inflation factors.

Table Sv. Hidradenitis suppurativa quality of life among participants with self-diagnosed hidradenitis suppurativa

	Unable to Do Due to HS	Extremely / Very Much	Moderately	Slightly / Not at All	Not Relevant*
HiSQOL Assessments, n (%)					
<i>In the past 7 days, how much has your HS impacted:</i>					
(a) Walking	36 (9.0)	41 (10.3)	50 (12.5)	273 (68.3)	NA
(b) Exercising	37 (9.3)	55 (13.8)	49 (12.3)	259 (64.8)	NA
(c) Sleeping	NA	84 (21.0)	68 (17.0)	248 (62.0)	NA
(d) Washing Yourself	NA	86 (21.5)	59 (14.8)	255 (63.8)	NA
(e) Getting Dressed	NA	73 (18.3)	57 (14.3)	270 (67.5)	NA
(f) Concentrating	NA	81 (20.3)	73 (18.3)	246 (61.5)	NA
<i>In the past 7 days, how has HS influenced:</i>					
(g) What You Wear to Avoid Discomfort	NA	80 (20.0)	90 (22.5)	230 (57.5)	NA
<i>In the past 7 days, due to HS, how impacted have you been by:</i>					
(h) Pain	NA	63 (15.8)	96 (24.0)	241 (60.3)	NA
(i) Itch	NA	119 (29.8)	106 (26.5)	175 (43.8)	NA
(j) Drainage	NA	63 (15.8)	81 (20.3)	256 (64.0)	NA
(k) Odor	NA	52 (13.0)	64 (16.0)	284 (71.0)	NA
<i>In the past 7 days, how much has HS caused you to feel:</i>					
(l) Down or Depressed	NA	63 (15.8)	65 (16.3)	272 (68.0)	NA
(m) Embarrassed	NA	71 (17.8)	78 (19.5)	251 (62.8)	NA

(n) Anxious or Nervous	NA	71 (17.8)	81 (20.3)	248 (62.0)	NA
<i>In the past 7 days, how much has HS:</i>					
(o) Made Sexual Activities Difficult	47 (11.8)	35 (8.8)	31 (7.8)	217 (54.3)	70 (17.5)
(p) Affected Your Desire for Sexual Activities	NA	84 (21.0)	42 (10.5)	274 (68.5)	NA
<i>In the past 7 days, how much has HS influenced:</i>					
(q) Your Ability to Work or Study	42 (10.5)	52 (13.0)	46 (11.5)	230 (57.5)	30 (7.5)

*"Not Relevant" indicated "I am not sexually active" for "(o) Made Sexual Activities Difficult" and "I do not work or study" for "(q) Your Ability to Work or Study."

Abbreviations: HiSQOL, hidradenitis suppurativa quality of life; HS, hidradenitis suppurativa; NA, not applicable; SD, standard deviation.

Table Svi. Hidradenitis suppurativa symptom assessment sub-scores among participants with self-diagnosed hidradenitis suppurativa

	Total (n = 400)
Sub-Scores of HSSA, Mean (SD), Points	
Pain	3.8 (2.7)
Drainage	3.3 (2.7)
Redness	4.5 (2.7)
Tenderness	3.5 (2.7)
Swollenness	3.9 (2.6)
Skin Hardness	3.7 (2.6)
Hot Skin	3.3 (2.7)
Bad Smell	2.9 (2.7)
Itchiness	4.5 (2.9)

Abbreviations: HSSA, hidradenitis suppurativa symptom assessment; SD, standard deviation.

Table SviI. Current medication use and treatment satisfaction among participants with self-diagnosed hidradenitis suppurativa

	Current Medication Use, n (%)	Satisfaction with Currently Used Medication, n (%) ^a				
		Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied
Overall Treatment	324 (81.0)	17 (5.2)	116 (35.8)	122 (37.7)	55 (17.0)	14 (4.3)
Antibacterial Ointment	133 (33.2)	9 (6.8)	52 (39.1)	45 (33.8)	20 (15.0)	7 (5.3)
Acne Ointment	54 (13.5)	4 (7.4)	26 (48.1)	16 (29.6)	6 (11.1)	2 (3.7)
Oral Antibiotics	55 (13.8)	2 (3.6)	24 (43.6)	22 (40.0)	6 (10.9)	1 (1.8)
Oral Antiinflammation	82 (20.5)	3 (3.7)	35 (42.7)	29 (35.4)	14 (17.1)	1 (1.2)
Etretinate	14 (3.5)	0 (0.0)	4 (28.6)	5 (35.7)	4 (28.6)	1 (7.1)
Injection of Biologics	12 (3.0)	0 (0.0)	5 (41.7)	4 (33.3)	3 (25.0)	0 (0.0)
Surgery and/or Surgical Treatment	14 (3.5)	3 (21.4)	4 (28.6)	5 (35.7)	1 (7.1)	1 (7.1)
Other Medication Prescribed by Your Doctor	68 (17.0)	6 (8.8)	26 (38.2)	21 (30.9)	13 (19.1)	2 (2.9)
Over-the-counter Medication Use	70 (17.5)	0 (0.0)	25 (35.7)	26 (37.1)	16 (22.9)	3 (4.3)

^aThe sample sizes of each currently used medication are not equal to the total sample size of 400 because the sample sizes represent only those who reported use of the designated medication.