Burden of Hidradenitis Suppurativa: A Systematic Literature Review of Patient Reported Outcomes

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SUPPLEMENTARY MATERIAL

Table S1a: Embase Search

#	Searches	Results
1	exp *suppurative hidradenitis/	4073
2	Hidradenitis suppurativa.ti,ab,kw.	4813
3	acne inversa.ti,ab,kw.	643
4	or/1-3	5106
5	patient$ perspective$.tw.	16296
6	patient$ preference$.tw.	20006
7	daily activit$.tw.	29162
8	(activit$ of daily living or activit$ of daily life).tw.	46386
9	patient$ reported symptom$.tw.	3253
10	patient$ reported outcome$.tw.	39483
11	PRO.tw.	324390
12	survey.tw.	744220
13	scale.tw.	1078152
14	diar$.tw.	221581
15	self-report$.tw.	228076
16	function$ status.tw.	41929
17	questionnaire$.tw.	821212
18	psychometric.tw.	57985
19	instrument$.tw.	392289
20	measure$.tw.	4551898
21	interview$.tw.	496056
22	focus group$.tw.	66326
23	quality of life.tw.	491148
24	QOL.tw.	81772
25	health-related quality of life.tw.	70968
26	HRQL.tw.	6354
27	HRQoL.tw.	30424
28	satisfaction.tw.	210910
29	well being.tw.	108512
30	emotional.tw.	227684
31	(cope or coping).tw.	117794

32	patient-reported.tw.	71600
33	fatigue.tw.	167742
34	(sf12 or sf 12 or short form 12 or shortform 12 or short form12 or shortform12 or sf twelve or sftwelve or shortform twelve or short form twelve).tw.	10458
35	(sf36 or sf 36 or short form 36 or shortform 36 or short form36 or shortform36 or sf thirtysix or sfthirtysix or shortform thirtysix or short form thirtysix).tw.	44664
36	(EQ-5D or EuroQol-5D or EQ 5D or EuroQol 5D).tw.	19485
37	((work productivity adj2 activity impairment) or WPAI).tw.	2470
38	clinical outcome/	192957
39	(clinician reported or clinician-reported).tw.	1047
40	((care giver or care-giver or caregiver) adj reported).mp.	1166
41	clinical outcome$ assessment$.mp.	785
42	(clinro or COA or PRO).mp.	407384
43	outcome assessment/ or patient-reported outcome/	627726
44	questionnaire/ or "quality of life"/	1180789
45	DLQI.ti,ab,kw.	3910
46	dermatology life quality index.ti,ab,kw.	3896
47	mental health/	157283
48	numeric rating scale/	10898
49	social interaction/	60761
50	sexual health/	17799
51	visual analog scale/	98849
52	patient global impression of severity/	17
53	itch.tw.	9300
54	(Treatment Satisfaction Questionnaire for Medication or TSQM-9).tw.	592
55	(Patient Health Questionnaire-9 or PHQ- 9).tw.	9499
56	(Columbia-Suicide Severity Rating Scale or C-SSRS).tw.	617
57	physician$ global assessment$.tw.	4995
58	patient$ global assessment$.tw.	3695
59	or/5-58	8571391
60	4 and 59	1793
61	limit 60 to (english language and yr="2000-current")	1723
62	limit 61 to (conference abstract or conference paper or "conference review" or editorial or erratum or letter or note)	914

63	61 not 62	809

Table S1b: Medline Search

#	Searches	Results
1	exp Hidradenitis Suppurativa/	2352
2	Hidradenitis suppurativa.mp.	3405
3	acne inversa/	2352
4	acne inversa.ti,ab,kw.	425
5	or/1-4	3441
6	patient$ perspective$.tw.	10724
7	patient$ preference$.tw.	12809
8	daily activit$.tw.	19090
9	(activit$ of daily living or activit$ of daily life).tw.	32446
10	patient$ reported symptom$.tw.	1578
11	patient$ reported outcome$.tw.	22640
12	PRO.tw.	213505
13	survey.tw.	578680
14	scale.tw.	807711
15	diar$.tw.	150981
16	self-report$.tw.	173650
17	function$ status.tw.	27629
18	questionnaire$.tw.	566627
19	psychometric.tw.	47888
20	instrument$.tw.	304398
21	measure$.tw.	3538277
22	interview$.tw.	391589
23	focus group$.tw.	52908
24	quality of life.tw.	310540
25	QOL.tw.	43136
26	health-related quality of life.tw.	48896
27	HRQL.tw.	3706
28	HRQoL.tw.	18575

29	satisfaction.tw.	150399
30	well being.tw.	87766
31	emotional.tw.	169770
32	(cope or coping).tw.	92300
33	patient-reported.tw.	39465
34	fatigue.tw.	103974
35	(sf12 or sf 12 or short form 12 or shortform 12 or short form12 or shortform12 or sf twelve or sftwelve or shortform twelve or short form twelve).tw.	6503
36	(sf36 or sf 36 or short form 36 or shortform 36 or short form36 or shortform36 or sf thirtysix or sfthirtysix or shortform thirtysix or short form thirtysix).tw.	27496
37	(EQ-5D or EuroQol-5D or EQ 5D or EuroQol 5D).tw.	10434
38	((work productivity adj2 activity impairment) or WPAI).tw.	744
39	clinical outcome$ assessment$.tw.	360
40	(clinician reported or clinician-reported).tw.	549
41	((care giver or care-giver or caregiver) adj reported).mp.	826
42	clinical outcome$ assessment$.mp.	409
43	(clinro or COA or PRO).mp.	310448
44	outcome assessment/ or patient-reported outcome/	9297
45	questionnaire/ or "quality of life"/	668157
46	DLQI.ti,ab,kw.	1707
47	dermatology life quality index.ti,ab,kw.	2088
48	Pain Measurement/	90494
49	numeric rating scale.tw.	4435
50	Mental Health/	46415
51	(visual analogue scale$ or VAS).ti,ab,kw.	66910
52	Sexual Health/	1570
53	Social Interaction/	708
54	patient global impression of severity.mp.	58
55	itch.tw.	5550
56	(Treatment Satisfaction Questionnaire for Medication or TSQM-9).tw.	230
57	(Patient Health Questionnaire-9 or PHQ- 9).tw.	5716
58	(Columbia-Suicide Severity Rating Scale or C-SSRS).tw.	277
59	physician$ global assessment$.tw.	2007
60	patient$ global assessment$.tw.	1654

61	or/6-60	6207367
62	5 and 61	805
63	limit 62 to english language	769
64	limit 63 to yr="2010- Current"	700
65	limit 64 to (comment or editorial or lecture or letter)	66
66	64 not 65	634

Table S1c: PsycINFO Search

#	**Searches**	**Results**
1	hidradenitis suppurativa.ti,ab.	8
2	acne inversa.ti,ab.	1
3	1 or 2	8
4	limit 3 to english language	6
5	limit 4 to yr="2010 -Current"	6

Table S2: General Characteristics of the included publications

Author, year	Study design	Type of data/data source	Country	Study Start Date	Study End date	PRO instrument	Primary Outcomes
Aarts, 2021(1)	Case-control	Outpatient clinic	Netherlands	2020	2021	NRS	Central Sensitization (alteration & amplification of pain perception)
Agut-Busquet, 2019(2)	Cross-sectional	Hospital database	Spain	2015	2017	DLQI, PtGA	HS severity and clinical characteristics
Andersen, 2020(3)	Case-control	Medical records	Denmark	2017	2018	Body Image Quality of Life Inventory (BI_QoLI), Hospital Anxiety and Depression Scale (HADS)	HRQoL
Andersen, 2018(4)	Cross-sectional	Medical records	Denmark	2013	2016	DLQI, MDI, EQ-5D VAS	HRQoL
Benhadou, 2021 (CA)(5)	Cohort	Medical records	NR	NR	NR	DLQI, VAS	Clinical characteristics of HS patients
Caposiena, 2021(6)	Cohort	Hospital database	Italy	2016	2019	DLQI, VAS	Flares outbreaks
Condamina, 2021(7)	Cross-sectional	Medical records	France	2017	2020	DLQI	Clinical characteristics of HS
Cuenca-Barrales, 2019C(8)	Cross-sectional	Investigator collected	Spain	2018	2018	PtGA_HS, NRS (pain), NRS (Pruritus), NRS (Malodour), NRS (Suppuration), FSFI-6, IIEF-5	Frequency of sexual distress, associated epidemiological and clinical factors
Cuenca-Barrales, 2020® (9)	Cross-sectional	Online questionnaire hosted by the Spanish hidradenitis	Spain	2018	2018	PtGA_HS, NRS (Pain), NRS (Pruritus), NRS (Malodour), NRS (Suppuration), FSFI-6, IIEF-5	Frequency of sexual dysfunction and potential risk factors

Author, year	Study design	Type of data/data source	Country	Study Start Date	Study End date	PRO instrument	Primary Outcomes
		suppurativa patients' association (ASENDHI)					
Cuenca-Barrales, 2020®(10)	Cross-sectional	Online questionnaire hosted by the Spanish hidradenitis suppurativa patients' association (ASENDHI)	Spain	2018	2018	PtGA_HS, NRS (Pain), NRS (Pruritus), NRS (Malodour), NRS (Suppuration)	Factors associated with fear of rejection, perceived attractiveness, interference in relationships
Cuenca-Barrales, 2019 (CA)*(11)	Cross-sectional	Online questionnaire hosted by the Spanish hidradenitis suppurativa patients' association (ASENDHI)	Spain	2018	2018	FSFI-6, IIEF-5	Frequency of sexual dysfunction (SD)
Cuenca-Barrales, 2021 (12)	Cohort	Hospital database	Spain	2017	2019	NRS (Suppuration), DLQI	Cardiovascular Risk Factor Profile
Fabbrocini, 2021(13)	Cohort (Primary data)	Outpatient clinic	Italy	2016	2017	HIDRAdisk, Skindex-16, DLQI, WPAI:GH	Wellbeing, Work activity
Frings, 2019(14)	Cross-sectional	University Medical Centre	Germany	NR	NR	DLQI, VAS, HADS-D/A, HADS-D/D	Psychological burden of HS patients
Garcovich, 2020(15)	Cross-sectional	Registry data	Italy	2019	2020	Pain-DETECT tool (PDQ)	Characteristics of Pain in HS, PROs on Pain and Pruritus
Garg, 2020(16)	Cross-sectional	Survey data	Multinational	2017	2018	HiSQOL, NRS	Pain and symptoms, life impact, comorbid conditions, and treatment
Grimstad, 2019(17)	Cohort	Registry data	Norway	2013	2016	DLQI	HRQoL

Author, year	Study design	Type of data/data source	Country	Study Start Date	Study End date	PRO instrument	Primary Outcomes
Hafner, 2021(18)	Cohort	Post marketing data	Multinational	NR	NR	NRS, DLQI, PHQ-9, EQ-5D, WPAI-HS	HS Clinical Response
Jorgensen2, 2021(19)	Cross-sectional	Hospital database	Denmark	2018	2019	DLQI, VAS	Pain alleviating methods, distress related to HS
Jorgensen, 2021(20)	Cohort	Hospital database	Denmark	2016	2019	DLQI, NRS (Distress), NRS (pain)	Treatment effectiveness
Kashetsky, 2021(21)	Cross-sectional	Survey data	Canada	2020	2020	HS Patient Experience (HSPE) survey	HRQoL (work, social life, family life, intimacy)
Krajewski 2, 2021(22)	Cross-sectional	Outpatient clinic	Germany	2017	2020	Worst Pain NRS (WP- NRS)	Pain evaluation
Krajewski, 2021(23)	Cross-sectional	Outpatient clinic	Germany	2017	2020	DLQI, WP-NRS	HRQoL
Janse, 2017(24)	Cross-sectional	University Medical Centre	Netherlands	2015	2015	VAS, PGA, DLQI, FSFI, IIEF, Arizona Sexual Experience	HRQoL (sexual impact of HS)
Jorgensen, 2020(25)	Cohort	Hospital database	Denmark	2016	2019	DLQI	Factors affecting HRQoL of HS patients
Katoulis, 2017(26)	Cross-sectional	Hospital database	Greece	2015	2016	DLQI	HRQoL
Kirby, 2017(27)	Cross-sectional	Medical records	USA, Denmark	2014	2016	DLQI	HRQoL
Kaaz, 2018(28)	Case-control	Medical records	Poland	NR	NR	VAS (pain), VAS (Itch), Athens Insomnia Scale (AIS), PSQI, DLQI	Sleep quality assessment, HRQoL
Kimball, 2020(29)	Cross-sectional	Registry data	Multinational	2013	2015	DLQI, CDLQI, HADS, HSSA, HSIA, WPAI:SHP	HRQoL
Katoulis, 2019 (CA)*(30)	Cohort	Registry data	Greece	2016	2018	DLQI	Epidemiological factors, HRQoL
Kolli, 2019 (CA)*(31)	Cross-sectional	Outpatient clinic	USA	NR	NR	DLQI, PHQ-9, PANAS	NR
Kolli, 2019 (CA)*(32)	Cross-sectional	Outpatient clinic	USA	NR	NR	DLQI, PHQ-9, BFNE	NR

Author, year	Study design	Type of data/data source	Country	Study Start Date	Study End date	PRO instrument	Primary Outcomes
Kolli, 2019 (CA)*(33)	Cross-sectional	Outpatient clinic	USA	NR	NR	DLQI, PHQ-9, Feelings of Stigmatization Questionnaire	NR
Kremer, 2019(34)	Cross-sectional	Survey data	USA	NR	NR	SF-12- PCS-12, SF-12- MCS-12	Physical and mental health
Marzano,2021(35)	Cohort	Hospital database	Italy	2016	2018	DLQI, VAS	Clinical response to ADA and its impact on HRQoL
Matusiak, 2018(36)	Cross-sectional	NR	Poland	NR	NR	DLQI, NRS (pain), NRS (Pruritus), VAS (pain), VAS (Pruritus) (), 4-Item Itch Questionnaire	Pruritus and pain intensity
McKenzie, 2020(37)	Cohort	Medical records	USA	2009	2018	DLQI	HRQoL, HS Symptoms
Molina-Leyva, 2020(38)	Cross-sectional	Outpatient clinics	Spain	2017	2019	NRS, DLQI	Pruritus and Malodour intensity, HRQoL
Nielsen, 2020(39)	Cross-sectional	Outpatient clinics	Denmark	2017	2018	McGill Pain Questionnaire	Pain perception and symptoms of depression and anxiety
Onderdijk, 2013(40)	Case-Control	Medical records	Netherlands/ Denmark	2009	2009	DLQI, MDI, NRS (Pain), NRS (itch)	Prevalence of depression
Pavon Blanco, 2019(41)	Cross-sectional	Hospital database	United Kingdom	2014	2015	PHQ-2, Generalized Anxiety Disorder-2 (GAD-2), DLQI	HS severity, depression, anxiety and QoL
Riis, 2016(42)	Cross-sectional	Survey data	Denmark	NR	NR	EQ-5D, EQ-5D VAS, VAS(Pain), VAS (Pruritus), VAS (Malodour), VAS (joint pain)	Disutility of HS patients measured by EQ-5D index and EQ-5D visual analogue scale (VAS) scores
Rondags, 2019(43)	Cross-sectional	Registry data	Netherlands	2015	2017	DLQI	Quality of life, severity of HS
Romani, 2020 (CA)(44)	Cross-sectional	Hospital database	NR	NR	NR	DLQI	HRQoL

Author, year	Study design	Type of data/data source	Country	Study Start Date	Study End date	PRO instrument	Primary Outcomes
Sampogna, 2020(45)	Cross-sectional	Medical records	Italy	2016	2019	Skindex-17, DLQI, SF-16, VAS (pain)	Depression, severity, Quality of Life, and health status
Sampogna 2, 2021(46)	Cross-sectional	IDI-IRCCS Registry	Italy	2016	2019	Skindex-17, SF-36 (pain), VAS	Relationship between Pain and clinical severity
Sampogna, 2021(47)	Cross-sectional	IDI-IRCCS Registry	Italy	2016	2019	Short Form Health Survey (SF-36), SF-12	HRQoL
Schneider-Burrus, 2021(48)	Cross-sectional	Outpatient clinic	Germany	2012	2017	DLQI	HRQoL
Schneider-Burrus, 2019 (CA)(49)	Cohort	NR	NR	NR	NR	WAI, WPAI	Work productivity
Senthilnathan, 2019(50)	Cross-sectional	Survey data	USA	2018	2018	DLQI, PHQ-9, PANAS	Emotional wellbeing
Senthilnathan, 2019 (CA)(51)	Cross-sectional	Survey data	USA	NR	NR	PHQ-9	Depression severity
Tavora, 2017(52)	Cross-sectional	Survey data	Brazil	2016	2017	DLQI	HRQoL
Taylor, 2021(53)	Cross-sectional	National Hospital Ambulatory Medical Care Survey	USA	2006	2017	NRS	Pain severity
Vlaeminck-Guillem , 2021 (CA)(54)	Cross-sectional	Questionnaires	NR	NR	NR	DLQI, VAS, Toronto Alexithymia Scale, 6-item Stigmatization Scale, 33-Item Feelings of Stigmatization Questionnaire	Feelings about pain, HRQoL, alexithymia, and stigmatization
Vossen, 2017(55)	Cross-sectional	Hospital database	Netherlands	NR	NR	NRS, 5-D itch scale	Prevalence and characteristics of pruritus, impact of pruritus

Author, year	Study design	Type of data/data source	Country	Study Start Date	Study End date	PRO instrument	Primary Outcomes
Van Straalen, 2021(56)	Cohort	Medical records	Multinational	2018	2019	DLQI, NRS (Pruritus), NRS (pain)	HS Clinical Response and PROMs
142+, 2020(57)	Cross-sectional	Outpatient clinic	Denmark	May 2018	November 2018	DLQI, VAS, WPAI	Impact of HS on work life

Abbreviations: **ADA**: adalimumab; **BFNE**: Brief Version of Fear of Negative Evaluation; **BRCS**: Brief Resilient Coping Scale; **CDLQI**: Children's Dermatology Life Quality Index; **DLQI**: Dermatology Life Quality Index; **EQ-5D**: Euro Quality of Life 5 Dimensions; **FSFI**: Female Sexual Function Index; HADS: Hospital Anxiety and Depression Scale; **HADS-D/A**: Hospital Anxiety and Depression Scale_Anxiety; **HADS-D/D**: Hospital Anxiety and Depression Scale_Depression; **HIDRAdisk**: a new innovative tool designed for rapid assessment of HS burden; **HiSQoL**: Hidradenitis Suppurativa Quality of Life instrument; **HRQoL**: Health-related quality of life; **HSSA**: Hidradenitis Suppurativa Symptom Assessment; **HSIA**: Hidradenitis Suppurativa Impact Assessment; ; **IIEF-5**: 5-item International Index of Erectile Function questionnaire; **MDI**: Major Depression Inventory Questionnaire; **NRS:** Numeric rating Scale; PANAS: The Positive and Negative Affect Schedule; **PGA**: Patient's global assessment of skin pain; **PHQ-9**: Patient Health 9-Item Questionnaire; **PROM**: Patient reported outcome measure; **PSQI**: Pittsburgh Sleep Quality Index; **PtGA_HS**: Patient's Global Assessment of Hidradenitis Suppurativa; **SF-12-PCS-12**: Short Form 12 Health Survey-physical health composite scores-12, **SF-12-MCS-12**: Short Form 12 Health Survey-mental health composite scores 12; **VAS**: Visual Analog Scale**; QoL**: quality of life; **WAI**: Work Ability Index; **WPAI:GH**: Work Productivity and Activity Impairment-General Health; **WPAI-HS**: Work Productivity and Activity Impairment-HS; **WPAI:SHP**: Work Productivity and Activity Impairment: Specific Health Problem

® Two publications for the HS Spanish population; *Secondary publications

(CA) refers to conference abstract

Table S3. Characteristics of HS patients

Author Year	HS Study group	Sample size (n)	Age (years)		Females (%)	Positive family history of HS (%)	Current Smokers (%)	BMI (kg/m^2)		HS Duration	HS severity	Use of biologics
			Mean	SD/range				Mean	SD/ range	Mean (SD)	Hurley Stages I/II/III	
Aarts 2021(1)	Adults, overall	100	34.5	27.3- 48.8	71	32	69	28.9*	24.7-33.3 **	NR	64/34/2	NR
Agut-Busquet 2019(2)	Adults, Nape lesions	30	NR	NR	10	65.5	68.3	25.96	4.3	NR	NR	NR
	Adults, No Nape lesions	347	NR	NR	45.4	38.2	65.5	29.7	6.8			
Andersen 2020(3)	Adults, overall	141	44	13.5	79	NR	46	31.9	7.3	18(14-25)	NR	NR
Andersen 2018(4)	Adults, overall	503	41	13	62.5	38.5	53	31.3	7.3	21(12.8)	NR	
Benhadou 2021 (CA)(5)	Adults and Adolescents, overall	1653	NR	NR	63	NR	NR	NR	NR	NR	NR	NR
	Adults and Adolescents, Women only	NR	20	NR	100	NR	76	NR	NR	NR	42/41/17	
	Adults and Adolescents, Men only	NR	22	NR	0	NR	89	NR	NR	NR	57/36/7	
Caposiena 2021 (6)	Adults and Adolescents, overall	115	34.4	11.5	53	21.7	68.7	27.5	6.2	13.6 (8.8)	0/68/47	100% ADA
Condamina 2021(7)	Adults, overall	396	38.1	10.1	85.6	21	57.3	NR	NR	NR	54/263/76	5.6% ADA
	Adults, Women only	339	37.5	7.6	100	21.5	56.4	NR	NR		47/231/60	
	Adults, Men only	57	41.9	12	0	17.50	61.4	NR	NR		7/32/16	

Author Year	HS Study group	Sample size (n)	Age (years)		Females (%)	Positive family history of HS (%)	Current Smokers (%)	BMI (kg/m^2)		HS Duration	HS severity	Use of biologics
			Mean	SD/range				Mean	SD/ range	Mean (SD)	Hurley Stages I/II/III	
Cuenca-Barrales, 2020 (A) (AC)(8-11)	Adults, overall	386	37.81	9.26	79	NR	57.8	29.35	6.71	17.77(9.6)	68/55/13	13.7% ADA
	Adults, Women only	306	37.44	8.69	100	100	NR	29.67	7	18.33(9.3)	174/149/25	
	Adults, Men only	80	39.21	11.15	NA	NA	NR	28.12	5	15.64(10.53)	144/102/42	
Cuenca-Barrales 2021 (12)	Adults, Follicular phenotype †	117	38.01	1.22	61.5	45.3	NR	30.89	0.65	12.68 (0.95)	4.26 (0.65) #	2.56% ADA
	Adults, Inflammatory phenotype ††	112	42.19	1.25	45.5	50	NR	30.47	0.67	15.02 (0.97)	12.22 (0.66) #	24.11% ADA
Garcovich 2020 (15)	Overall	110	30	23	49%	26.6	66.4%	24.69	5.96	10±12.5	30/50/30	18.2% biologics
Grimstad 2019(17)	Adults, overall	255	39.3	9.91	74	NR	56.9	30.07	5.97			NR
Hafner 2021 (18)	Adults, overall	201	37	12	49	25	64	30.1	6.4	NR	4/90/107	NR
Fabbrocini 2021(13)	Adults, overall	308	35.2	12.9	56.2	NR	66.2	27.5	16–46	3.9 (5.2)	92/123/73	16.4% immune-suppressants
Frings 2019(14)	Adults, overall	110	38	12	55	NR	37	30.5	6.9			NR
Garg 2020(16)	Adults, overall	1299	30.7	10.9	84.9	NR	44.0	NR	NR	10.2(8.9)	NR	NR

Author Year	HS Study group	Sample size (n)	Age (years)		Females (%)	Positive family history of HS (%)	Current Smokers (%)	BMI (kg/m^2)		HS Duration	HS severity	Use of biologics
			Mean	SD/range				Mean	SD/ range	Mean (SD)	Hurley Stages I/II/III	
Janse 2017(24)	Adults, overall	300	45.9	NR	78	NR	59.8	27.9	5.9	20 (12)	70/97/67 women 26/26/14 men	NR
Jorgensen 2020(25)	Adults, overall	339	39.7	13.5	64.3	NR	75.2	29	7.1	13.8 (11.5)	96/195/48	NR
Jorgensen 2021(20)	Adults overall	108	39.4	13.9	67.6	43.5	62	28.8	6.3	14(11.5)	25/70/13	¥¥
	Tetracycline	32	39.2	14.1	65.6	46.9	69	28.3	5.5		10/16/6	
	Doxycycline	31	39.8	16.2	67.7	48.4	64	28.7	6.6		6/21/4	
	Lymecycline	45	39.4	12.3	70.5	38.6	57	29.2	6.7		9/32/3	
Jorgensen 2021(19)	Adults, overall	134	38.3	12.8	71	40	75	30	17-51	NR	43/70/21	NR
Kaaz 2018(28)	Adults and Adolescents, with sleep disorders	108	36.3	12.1	47.2	NR	18.0	28.8	5.4	9.1(8.3)	50/49/9	NR
Katoulis 2019(CA)*(30)	Adults, overall	208	36.67	12.84	53.8	22.1	74.50	NR	NR	NR	58/63/87	NR
Katoulis 2017(26)	Adults and Adolescents, overall	152	37.4	13.5	60.5	32.2	72.4	30.4	6.7	1-48	40/68/44	NR
Kimball 2020(29)	Adults only	529	38.6	12.6	68.6	NR	NR	NR	NR	5.8(9.5)	28/346/155	NR
	Adolescents only	64	15.6	1.4	78.5	NR	NR	NR	NR	4.6 (5.6)	12/48/5	NR
Kirby 2017(27)	Adults, Denmark site	96	41.6	13.6	79.2	NR	NR	NR	NR	NR	NR	NR

Author Year	HS Study group	Sample size (n)	Age (years)		Females (%)	Positive family history of HS (%)	Current Smokers (%)	BMI (kg/m^2)		HS Duration	HS severity	Use of biologics
			Mean	SD/range				Mean	SD/ range	Mean (SD)	Hurley Stages I/II/III	
	Adults, US site	58	39.8	13.3	93.1	NR	NR	NR	NR	NR	NR	NR
Kolli 2019(CA)*(31-33)	Adults, overall	150[∞]	40	NR	92	NR	NR	NR	NR	NR	NR	NR
Kashetsky 2021(21)	Adults, overall	537	38	14-73	95	NR	NR	NR	NR	NR	NR	NR
Krajewski 2021(22, 23)	Adults, Light therapy	1795	40	11.8	64	NR	55.6	28.1	6.2	NR	425/ 1061 /309	NR
Kremer 2019(34)	Adults, overall	209	37.2	NR	NR	NR	NR	NR	NR			NR
Marzano 2021(35)	Adults, overall	389	34*	25-46 [**]	49	20.90	63.6	NR	NR	NR	17 (11-27) [##]	27.35 Immuno-suppressants
Matusiak 2018(36)	Adults and Adolescents, overall	103	35.6	13.2	48.5	NR	13	29.4	5.7	9.3 (7.4)	29/41/10	NR
	Adults and Adolescents, with pain	80	34.9	12.2	48.8	NR	12	29.8	5.7			
	Adults and Adolescents, with pruritus	43	34.7	12.1	58.1	NR	8	30	6			
McKenzie 2020(37)	Overall	145	32.7	15-65	64.8	NR	NR	30.1	19-60	21.9 (6-63.5)	23/72/26	NR
Molina-Leyva 2020(38)	Adults, overall	233	40.14	13.46	57	47.6	100	30.68	7.05	14(11)	70/97/66	NR

Author Year	HS Study group	Sample size (n)	Age (years)		Females (%)	Positive family history of HS (%)	Current Smokers (%)	BMI (kg/m^2)		HS Duration	HS severity	Use of biologics
			Mean	SD/range				Mean	SD/ range	Mean (SD)	Hurley Stages I/II/III	
Murlidharan 2021(58)	Adults, overall	101	NR	NR	NR	NR	NR	NR	NR		NR	NR
Nielsen 2020 (39)	Adults, overall	138	44*	33-54**	80	NR	46	30.9*	26.8-35.6**	18 (14–25)	- ****	NR
Onderdijk 2013(40)	Adults and Adolescents, overall	211	43	11.8	77	NR	NR	NR	NR	16.8 (11.6)	30/56/14	NR
Pavon Blanco 2019(41)	Adults and Adolescents, overall	211	38.2	11.8	60	NR	41	NR	NR	NR	45/64/109	NR
Riis 2017(42)	Adults, overall	294	42.38	12.12	79	40.5	NR	NR	NR	22.2 (12.7)	NR	NR
Romani 2020(CA)(44)	Adults, overall	229***	37.64	NR	10.9	NR	NR	NR	NR	NR	NR	NR
Rondags 2019(43)	Adults, overall	492	39	12.4	72.3	NR	54.6	28.5	6	NR	205/114 /114~	NR
Sampogna 2021(46)	Adults and Adolescents, overall	298	31.9	12	63.8	NR	NR	NR	NR	NR	NR	NR
Sampogna 2020(45, 47)	Adults & Adolescents, overall	341	32.4	11.9	61.6	NR	68	NR	NR	NR	NR	NR
Schneider-Burrus 2021(48)	Adults, overall	462	38.8	10.9	60.2	34	66.5	28.9	5.9	NR	NR	NR
Schneider-Burrus 2019 (CA)(49)	Adults, Employed	416	39.7*	11.5	54.1	NR	NR	31.0	6.9	NR	NR	NR

Author Year	HS Study group	Sample size (n)	Age (years)		Females (%)	Positive family history of HS (%)	Current Smokers (%)	BMI (kg/m^2)		HS Duration	HS severity	Use of biologics
			Mean	SD/range				Mean	SD/ range	Mean (SD)	Hurley Stages I/II/III	
Senthilnathan 2019 (CA)(50, 51)	Adults, overall	153[¥]	39	NR	89	NR	NR	NR	NR	NR	NR	NR
Taylor 2021(53)	Adults, Emergency department visit	- [©]	29.3	26.8- 31.7 [**]	82.8	NR	NR	NR	NR	NR	NR	NR
Tavora 2017(52)	Adults, overall	390	31*	25- 37	72	20	26	29*	25-33	13(8-20)	73/199/113	4% ADA
Van Straalen 2021(56)	Adults, Tetracycline	180	37*	26-46	58.9	34	61.8	29.81	6.1	NR	NR	NR
	Adults, Clindamycin and Rifampicin	103	36*	(27-45) [***]	54.4	35	56.6	29.21	6.2	10 (5-17)	14/58/31	NR
Vlaeminck-Guillem 2021 (CA)(54)	Adults and Adolescents, overall	127	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Vossen 2017(55)	Adults and Adolescents, overall	211	38*	29-49	64	38	62	28.5	5.9	14 (7-25)	32/140/39	NR
Yao 2020(57)	Adults & Adolescents, overall	100	38	16-68	56	NR	NR	29.7	17.3-51.1	15.2 (0.4 - 54)	40/47/13	

ADA, Adalimumab, NR, not reported, *Median, [**]IQR, [#] Mean and SD for the International Hidradenitis Suppurativa Severity Score System (IHS4), †Follicular phenotype: follicular lesions on a background of comedones and nodules with occasional abscesses. More common in women, less commonly fistular (tunnel) formation, non-coalescent lesions, ††Inflammatory phenotype: predominantly abscesses with occasional nodules in the absence of comedones. More frequently in men, more severe disease with more frequent fistulae and scarring,[##] Median using IHS4, [¥] 153 HS patients were included in the study but emotional well-being data was collected for 66 patients;[¥¥] Oral tetracycline-/lymecycline/doxycycline (25, 23.1%); Oral clindamycin and rifampicin (5, 4.6%) ∞ 150 HS patients were recruited but questionnaire was completed by 61 patients; [***] 25 women with vulvar lesions from a global sample of 229 women with HS © (-) refers to the visits to the emergency units by HS patients throughout the period of the study.~ HS_IHS4, ****Patients with HS were divided into subgroups according to disease severity (1–2 vs. ≥ 3 regions involved and 1 vs. ≥ 3 flares in the last 6 months).

(A) Three full texts and a conference abstract were derived from the same HS Spanish population. (CA) refers to conference abstrac

Table S4: Overall mean HRQoL total scores reported for the whole sample of HS patients in the included studies.

Author Year	Assessment Tool	Time point of data collection	Sample Size	Mean	SD	P value
Agut-Busquet 2019 (2)	DLQI	Baseline (patients without lesions in the nape) [#]	347	10.72	7.18	
Caposeina 2021(6)	DLQI	Baseline (patients on ADA)	115	15.1	9	NR
		52 weeks' follow up	101	7.2	6.8	
Cuenca-Barrales 2021(12)	DLQI	Baseline (inflammatory phenotype of HS) [€]	112	12.48	0.67	
Fabbrocini 2021(13)	DLQI	Baseline	308	10.8	8.1	
		3 months visit	285	9.2	7	NR
		9 months visit	253	8.6	6.9	
Frings 2019(14)	DLQI	Baseline	82	12	7	
Hafner 2021(18)	DLQI	Baseline	168	16.9	NR	
		52 weeks follow up	114	8.57	NR	<0.0001
Janse 2017(24)	DLQI	Baseline	300	12.5	7.5	
Jorgensen 2021	DLQI	Follow-up all patients*	108	9.5	6.5	
Kaaz 2018(28)	DLQI	Baseline	108	13	8	
Katoulis 2019	DLQI	Baseline	208	12.3	8.58	
Kimball 2020(29)	DLQI	Baseline	505	12.6	8.0	
Kirby 2017(27)	DLQI	Baseline	154	10.1	8.6	
Kolli 2019	DLQI	Baseline	61	31.2	9.6	
Krajewski 2021(23)	DLQI	Baseline	1795	13.2	8.1	
Marzano 2021(35)	DLQI	Baseline, patients treated with ADA	240	20[¥¥]	12-25[¥¥]	< 0.0001
		week 16	240	10 [¥¥]	7-18[¥¥]	
		week 52	240	7[¥¥]	4-14[¥¥]	
Matusiak 2018(36)	DLQI	Baseline	103	13.3	7.8	
Molina-Levya 2020(38)	DLQI	Baseline	233	10.93	7.3	
McKenzie 2020(37)	DLQI	Baseline	145	14.2	0-30	

Author Year	Assessment Tool	Time point of data collection	Sample Size	Mean	SD	P value
Murlidharan 2021	DLQI	Baseline (HS Patients on ADA for a minimum of 6 months)	48	NR∞	NR	
Onderdijk 2013(40)	DLQI	Baseline	211	8.4	7.5	
Pavon-Blanco 2019(41)	DLQI	Baseline	211	14.81	8.45	
Romani 2020(44)©	DLQI	Baseline	25	10.79 ¥¥	6.1	
Rondags 2019(43)	DLQI	Baseline	433	10¥¥	5-16¥¥	
Sampogna 2020(45)		Baseline for HS patients with depressionβ	60	17	6.7	
Schneider-Burrus 2021(48)	DLQI	Baseline	462	13.18	7.99	
Tavora 2019(52)	DLQI	Baseline	390	20 ¥¥	13-25 ¥¥	
Van Straalen 2021(56)	DLQI	Baseline, patients receiving Tetracyclines	180	13.3	7.5	0.07
		Baseline, patients receiving Clindamycin & Rifampicin	103	15.1	7.9	0.07
		Follow up 12 weeks	180	10.2	8.2	<0.001**
		Follow up 12 weeks	103	9.8	7.6	<0.001**
Yao 2020(57)	DLQI	Baseline	100	10.5	0 - 27¥¥	
Fabbrocini 2021(13)	HIDRAdisk	Baseline	308	65.7	23.3	
		3 Months Visit	285	60.1	24.4	
		9 Months Visit	253	53.1	26.5	NR
Kimball 2020(29)	HS Symptom Assessment (HSSA)	Baseline	521	4.8	2.8	NR
	HS Impact Assessment (HSIA)	Baseline	521	4.9	2.7	
Hafner 2021(18)	EQ-5D Utility Index	Baseline	197	0.46		
		52 weeks ADA ₹	141	0.72		
	EQ-5D Global Health status	Baseline	200	59.6		<0.0001

Author Year	Assessment Tool	Time point of data collection	Sample Size	Mean	SD	P value
		52 weeks ADA ₹	141	70.45		
Riis 2016(42)	EQ5D	Baseline	294	0.705	0.25	<0.0001****
Sampogna 2020(45)	SF-36 PCS¥	Baseline, HS patients with depression (GHQ≥7)	82	37.4	12	<0.001
		HS patients without depression (GHQ<7)	201	43.9	10.3	
	SF-36 MCS¥	Baseline, HS patients with depression (GHQ≥7)	82	26.7	10.4	<0.001
		HS patients, with depression (GHQ<7)	201	39.9	11.4	

DLQI total score ranges from 0 to 30; DLQI scores 2-5 = small effect on patient's life, 6-10 = moderate effect on patient's life, scores between 11-20 represent the disease having a very large impact on the patients' HRQoL.

Authors also provided data for mean DLQI scores at baseline for 30 HS patients with nape lesions (mean (SD)14.53 (7.17)), € Data was also provided for follicular phenotype of HS, * Data was also provided for patients treated with Doxycycline versus those treated with lymecycline, with a significant difference in the DLQI for the two groups of patients, ∞ Authors reported frequency of DLQI scores categories before and after adalimumab ** Compared with baseline scores, ¥¥ medians and/or interquartile ranges, β Authors also provided DLQI mean score for patients with HS but without depression (mean 9.3, SD 6.2, p<0.001 compared to patients with depression), © the population studied were HS patients with vulvar lesions, **** significant difference between HS patients and general population, GHQ: General Health Questionnaire, ¥ Components of SF-36, including physical component summary(PCS) and mental component summary (MCS)

Table S5: Mean HRQoL scores stratified by severity of HS (Hurley staging) at baseline in the included studies.

Author, Year	Assessment Tool	Severity category	Sample Size	Mean	SD	P value
Fabbrocini, 2021	HIDRAdisk***	Hurley Stage I	90	53.3	24.5	NR
		Hurley Stage II	134	67.1	20.4	
		Hurley Stage III	81	77.1	20.3	
Kimball 2020(29)	HS Symptom Assessment (HSSA)	Hurley Stage I	28	4.0	3.1	NR
		Hurley Stage II	340	4.4	2.8	
		Hurley Stage III	153	5.7	2.6	
		Hurley Stage I	28	4.1	2.9	
		Hurley Stage II	340	4.6	2.7	

Author, Year	Assessment Tool	Severity category	Sample Size	Mean	SD	P value
	HS Impact Assessment (HSIA)	Hurley Stage III	153	5.6	2.6	
Condamina 2021(7)	DLQI	Hurley Stage I	54	8.8	5.8	<0.0001
		Hurley Stage II	263	13.4	6.7	
		Hurley Stage III	76	17.8	6.1	
Jorgensen 2020(25)	DLQI	Hurley Stage I	NR	8.7	6.6	<0.001
		Hurley Stage II	NR	12.4	7.6	
		Hurley Stage III	NR	16.1	7.1	
Kimball 2020(29)¥	DLQI	Hurley Stage I	28	8.8	7.3	NR
		Hurley Stage II	330	11.6	7.5	
		Hurley Stage III	147	15.7	8.2	
Katoulis 2017(26)	DLQI	Hurley Stage I	40	10.7	7.5	0.024
		Hurley Stage II	68	10.0	6.5	
		Hurley Stage III	44	16.8	8.3	
McKenzie 2020(37)	DLQI	Hurley Stage I	23	11.3	5-19**	<0.001
		Hurley Stage II	72	13.9	8.8-21**	
		Hurley Stage III	26	20.2	13-27**	
Schneider-Burrus 2021(48)	DLQI	Hurley Stage I	NR	8.7	6.6	<0.001
		Hurley Stage II	NR	12.4	7.6	
		Hurley Stage III	NR	16.1	7.1	
Rondags 2019(43)	DLQI	Refined Hurley Classification: Stage IA (Mild)	127	7 *	3-13 *	
		Stage IB (Moderate)	27	9 *	7-13 *	
		Stage IC (Severe)	49	13 *	6.5-18.5 *	
		Stage IIA (Mild)	27	9 *	2-16 *	
		Stage IIB (Moderate)	87	10 *	6-15*	
		Stage IIC (Severe)	78	13*	6.75-19*	
		Stage III	38	16.5 *	12-21*	

***0 = no impact of the disease on HRQoL; 100 = maximum impact of disease on HRQoL, *Medians and interquartile ranges were reported, ** Range was reported, ¥ Kimball 2020 also reported data for adolescent HS patients stratified by Hurley stages.

Table S6: Mean HRQoL scores stratified by sex at baseline in the included studies.

Author, Year	Assessment Tool	Study Group	Sample Size	Mean	SD	P value
Benhadou 2021(5)	DLQI	Females	1041	14.0	NR	< 0.001
		Males	612	12.0	NR	
Fabbrocini 2021(13)	HIDRAdisk*	Females	173	67.8	23.9	0.019
		Males	135	63	22.3	
	DLQI	Females	173	11.4	8.3	0.121
		Males	135	9.9	7.8	
Janse 2017(24)	DLQI	Females	234	12.8	7.5	0.33
		Males	66	11.7	7.4	
Krajewski 2021(23)	DLQI	Females	1152	14.2	8	<0.001
		Males	643	11.5	8	
Jorgensen 2020(25)	DLQI	Females	218	11.9	7.6	NR
		Males	121	11.8	7.7	

* (0 = no impact of the disease on HRQoL; 100 = maximum impact of disease on HRQoL)

Table S7: Mean HS related pain scores in the included studies

Author Year	Pain Assessment Tool	Study Group	Time-point of data collection	Sample Size	Score Mean	SD	P Value
Aarts 2021(1)	NRS	HS Patients_Overall	Baseline	100	3*	0-3*	
Cuenca-Barrales 2021(12)[#]	NRS	HS patients, Inflammatory phenotype	Baseline	112	5.18	0.32	0.02
		HS patients, Follicular phenotype	Baseline	117	4.19	0.31	
Cuenca-Barrales 2020 (9)	NRS	HS Patients_Overall	Baseline	386	6.54	2.95	
Caposiena 2021(6)	VAS	HS Patients_Overall	Baseline	115	6.5	2.5	
			52 Weeks Post ADA ₹	101	2.8	2.7	NR
Garg 2020(16)	NRS	HS Patients_Overall	Baseline	1299	5	2.8	

Author Year	Pain Assessment Tool	Study Group	Time-point of data collection	Sample Size	Score Mean	SD	P Value
Grimstad 2019(17)	NRS	HS Patients_Overall	Baseline	258	6.89	2.28	
Hafner 2021(18)	NRS	HS Patients_Overall	Baseline	198	5.87	NR	
			52 Weeks Post ADA ₨	141	3.2	NR	<0.0001
Jorgensen 2021(20)	NRS boil-related pain	HS Patients_Overall	Baseline	53	7.2	2.3	
			Baseline	15	7.7	2.1	
Molina-Leyva 2020(38)	NRS	HS Patients_Overall	Baseline	233	4.64	3.43	
Onderdijk 2013(40)	NRS	HS Patients_Overall	Baseline ¥	211	3.6	3.2	<0.001
Taylor 2021(53)	NRS	HS Patients_Overall	Baseline	38300	7.4	6.3-8.5 **	
Vossen 2017(55)	NRS	HS Patients_Overall	Baseline	211	3.7	3.3	NR
Sampogna 2020(45)	VAS	HS Patients_Overall	Baseline	341	NR	NR	
Yao 2020(57)	VAS	HS Patients_Overall	Baseline	100	6.1	0-10 **	
Frings 2019(14)	VAS	HS Patients_Overall	Baseline	NR	NR	NR	NR
Kaaz 2018(28)	VAS	HS Patients, VAS mean	Baseline	108	4.9	2.9	NR
		HS Patients, VAS max ***	Baseline	108	7.3	2.4	NR
Marzano 2021(35)	VAS	HS patients ₨ with ADA	Baseline	253	8*	6-9*	
			week 16	253	5*	3-6 *	< 0.0001
			week 52	253	3*	2-5 *	< 0.0001
Matusiak 2018(36)	VAS	HS Patients, with pain	Baseline	80	4.6	2.5	
	NRS	HS Patients, with pain	Baseline	80	4.9	2.4	
Riis 2016(42)	VAS	HS Patients_Overall	Baseline	294	3.91	3.18	

Author Year	Pain Assessment Tool	Study Group	Time-point of data collection	Sample Size	Score Mean	SD	P Value
	VAS_Joint Pain	HS Patients_Overall	Baseline	294	3.42	3.44	
	EQ-5D VAS Pain	HS Patients_Overall	Baseline	294	62	24.75	Significant [β]

* Authors reported median, ** Range, # The same data were also reported by Cuenca-Barrales 2019, *** The most intensive experienced within the last 3 days, ¥ authors reported also NRS scores for controls= 1.9, SD 2.6, controls included skin tumours (27%), Psoriasis (12%), eczema (19%), and acne (10%), β A significant difference between the general population and the HS cohort
NRS: Numeric Rating Scale, NS: Nonsignificant, VAS: Visual Analogue Scale

Table S8: Mean HS related pain scores at baseline across key subgroups (stratified by sex and HS severity)

Author, Year	Pain Assessment Tool	Study Group	Sample Size	Score Mean	SD	P Value
Cuenca-Barrales 2020(9)	NRS	Females	306	6.52	2.98	NR
		Males	80	6.64	2.81	
Benhadou 2021(5)	VAS	Females	1041	7.8	NR	< 0.011
		Males	612	7.4	NR	
Janse 2017(24)	VAS	Female Patients	234	4.9	2.7	NR
		Male Patients	66	3.9	2.9	
Jorgensen 2021(19)	VAS[¥]	Hurley Stage I	43	5.7	3.4	NR
		Hurley Stage II	70	5.7	3.4	
		Hurley Stage III	21	8.4	2.3	
Sampogna 2021*(47)	VAS	VAS pain < 5	150	Hurley mean 1.6	NA	<0.001
		VAS pain 5-6	68	Hurley mean 1.7	NA	
		VAS pain ≥7	123	Hurley mean 2	NA	
Grimstad 2019(17)	NRS	Hurley Stage I	31	6.32	2.52	0.131
		Hurley Stage II	188	6.87	2.21	
		Hurley Stage III	36	7.44	2.34	

*Authors reported a significant positive association between HS severity (reported for Hurley, IHS4, & Sartorius score means) and pain (measured by different tools; VAS, SF36 and Skindex 17), ¥ reported as VAS score for distress due to pain, authors also reported VAS scores for boil related pain (4.4 (3.20, 6.4(3.10, 8.6(2.5) for Hurley I, II, and III respectively)

Table S9: Mean HS related pruritus scores at baseline in the included studies

Author, Year	Assessment Tool	Study Group	Sample Size	Score Mean	SD
Cuenca-Barrales 2021(12)	NRS	HS patients, Follicular phenotype	117	4.9	0.32
		HS patients, Inflammatory phenotype	112	4.14	0.32
Cuenca-Barrales 2020 (9)	NRS	HS Patients_Overall	386	6.43	2.96
Vossen 2017 (55)	NRS	HS Patients_Overall	211	6.1	2
Onderdijk 2013(40)	NRS	HS Patients_Overall	211	3.3	3.1
Kaaz 2018(28)	VAS	HS Patients_Overall	108	4.1	2.9
Matusiak 2018(36)	VAS	HS Patients with Pruritus	43	3.9	2.2
	NRS		43	4.3	2.1
Riis 2016(42)	VAS	HS Patients_Overall	294	3.72	3.17

Table S10: Mean scores reflecting the Mental Health impact of HS in the included studies.

Author Year	Assessment Tool	Study Group	Time-point of data collection	Sample Size	Score Mean	SD	P Value
Hafner 2021(18)	Patient Health 9-Item Questionnaire	HS Patients_Overall	Baseline	200	10.62	NR	
		HS Patients_Overall	52 weeks post ADA Rx	142	5.87	NR	<0.0001
Kimball 2020(29)	HADS_Depression	HS Patients_Overall	Baseline	508	5.8	4.4	NR
	HADS_Anxiety	HS Patients_Overall	Baseline	508	8.6	4.5	
	HADS__Depression	HS Patients_Overall Adolescents	Baseline	63	3.7	3.4	
	HADS_Anxiety	HS Patients_Overall - Adolescents	Baseline	63	6.6	4.6	
Sampogna 2020 (45)	SF-36 MCS	HS Patients, depressed (GHQ≥7)	Baseline	82	26.7	10.4	<0.001
	SF-36 MCS	HS Patients, Not depressed (GHQ<7)	Baseline	201	39.9	11.4	
Frings 2019(14)	HADS_ Anxiety	HS Patients_Overall	Baseline	80	7	4	
	HADS_ Depression	HS Patients_Overall	Baseline	80	6	4	
Pavon Blanco 2019(41)	Generalized Anxiety Disorder-2	HS Patients_Overall	Baseline	211	1.88	1.86	

Author	Year	Assessment Tool	Study Group	Time-point of data collection	Sample Size	Score Mean	SD	P Value
Kirby 2017(27)		HADS_depression	HS Patients_Overall	Baseline	154	8.6	4.8	

HADS: Hospital Anxiety and Depression Scale, MCS: Mental component score, SF-36: 36-Item Short Form Survey

Table S11: Mean scores at baseline reflecting the psychological impact of HS in the included studies stratified by HS severity.

Author, Year	Assessment Tool	Study Group	Sample Size	Score Mean	SD	P Value
Kimball, 2020(29)	HADS_Depression	Adults				
		Hurley Stage I	28	5.0	4.6	NR
		Hurley Stage II	332	5.6	4.4	
		Hurley Stage III	148	6.4	4.4	
	HADS_Anxiety	Adults				
		Hurley Stage I	28	8.3	4.6	NR
		Hurley Stage II	332	8.7	4.6	
		Hurley Stage III	148	8.5	4.3	
	HADS__Depression	Adolescents				
		Hurley Stage I	12	2.0	2.3	NR
		Hurley Stage II	46	3.9	3.4	
		Hurley Stage III	5	6.1	4.5	
	HADS_Anxiety	Adolescents				
		Hurley Stage I	12	4.5	3.0	NR
		Hurley Stage II	46	6.8	4.9	
		Hurley Stage III	5	9.6	2.1	

HADS: Hospital Anxiety and Depression Scale

Table S12: Mean scores reflecting the sexual impact of HS in the included studies.

Author Year	Assessment Tool	Study Group	Sample Size	Score Mean	SD	P Value
Janse 2017(24)	Female Sexual Function Index (FSFI)	Females	234	21.6	9.6	NA
	International Index of Erectile Function (IIEF)	Males	66	49.7	20.7	
	Arizona Sexual Experience (ASEX)	HS Patients Overall	300	16.7	5.3	
		Females	234	17.4	5.2	<0.001
		Males	66	14	4.7	
Cuenca-Barrales 2020(9)	6-item Female Sexual Function Index (FSFI-6)*	Females	306	2.55**	1.66	NA
	5-item International Index of Erectile Function questionnaire (IIEF-5)*	Males	80	3.28	1.86	

NA: Not applicable, * Shorter version of the Female Sexual Function Index with 6 items, and the International Index of Erectile Function with 5 items; ** This is the mean of the score obtained in the second question, in which the participant was asked to rate her sexual arousal during sexual activity or intercourse

Table S13: Mean scores reflecting the impact of HS on work and productivity.

Author, Year	Assessment Tool	Time-point of data collection	Sample Size	Score Mean	SD	P Value
Fabbrocini 2021	WPAI- General Health- Overall work impairment	Baseline	308	36	33.7	
	WPAI - General Health- Total activity impairment	Baseline	308	42.3	33.2	
Hafner 2021(18)	WPAI_Productivity impairment	Baseline	86	45.99	NR	
	WPAI_Productivity impairment	52 weeks ADA R+	69	30.45	NR	<0.0001
	WPAI _Activity impairment	Baseline	197	53.25	NR	
	WPAI _Activity impairment	52 weeks ADA R+	143	28.39	NR	<0.0001
Kimball 2020(29)	WPAI: Specific Health Problem (SHP)- Overall work impairment	Baseline	303	35.3	33.3	
	WPAI:SHP - Activity Impairment	Baseline	515	41.1	33.2	
		Baseline	13*	42.3	36.1	
	Absenteeism	Baseline	304	9.9	24.0	

Author, Year	Assessment Tool	Time-point of data collection	Sample Size	Score Mean	SD	P Value
	Presenteeism	Baseline	298	29.8	30.0	
Yao 2020(57)	WPAI_Total Activity Impairment	Baseline	100	32.7	30.6	
	Absenteeism	Baseline	50	7	21.4	
	Presenteeism	Baseline	53	21.3	26.1	
	Overall work impairment	Baseline	50	26.6	30.1	

WPAI: Work Productivity and Activity Impairment, * adolescent Hidradenitis suppurativa patients

Figure S1: ***Matrix presenting critical appraisal results of cross-sectional studies (New-Castle Ottawa Scale)¥***

Cross-sectional studies																																				
Items	Hafner, 2021	Janse, 2021	Jorgensen2, 2021	Senthilnathan, 2019	Condamina, 2021	Taylor, 2021	Murlidharan, 2021	Sampogna 2, 2021	Sampogna, 2021	Schneider, 2021	Cuenca-Barrales, 2020	Cuenca-Barrales 2, 2020	Garg, 2020	Kimball, 2020	Molina-Leyva, 2020	Nielsen, 2020	Sampogna, 2020	Yao, 2020	Cuenca-Barrales, 2019	Agut-Busquet, 2019	Frings, 2019	Pavon Blanco, 2019	Rondags, 2019	Matusiak, 2018	Kirby, 2017	Katoulis, 2017	Tavora, 2017	Vossen, 2017	Krajewski, 2021	Krajewski 2, 2021	Riis, 2016	Kremer, 2019	Kashetsky, 2021	Garcovich, 2020	Andersen, 2018
Patient Selection																																				
Representativeness of exposed cohort	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆		⋆	⋆	⋆
Sample size	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆
Non-respondents	⋆		⋆		⋆	⋆	⋆			⋆	⋆	⋆	⋆	⋆		⋆	⋆	⋆	⋆				⋆		⋆	⋆		⋆	⋆	⋆	⋆				⋆
Ascertainment of exposure		⋆		⋆	⋆	⋆		⋆	⋆	⋆⋆	⋆	⋆	⋆	⋆		⋆	⋆	⋆⋆	⋆	⋆	⋆⋆	⋆	⋆	⋆	⋆	⋆			*	⋆				⋆	⋆
Comparability																																				
Comparable participants; controlled confounders	⋆	⋆	⋆	⋆	⋆		⋆	⋆⋆	⋆⋆	⋆		⋆		⋆	⋆	⋆	⋆	⋆		⋆	⋆		⋆	⋆	⋆	⋆	⋆		*	⋆	⋆	⋆		⋆	⋆
Outcome																																				
Assessment of outcome	⋆	⋆	⋆	⋆	⋆⋆	⋆		⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆⋆	⋆⋆	⋆	⋆	⋆	⋆⋆	⋆⋆	⋆	⋆	⋆	⋆	⋆
Statistical test	⋆	⋆	⋆	⋆	⋆	⋆		⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆
Total Score	**6**	**6**	**6**	**6**	**8**	**6**	**4**	**7**	**7**	**8**	**6**	**7**	**6**	**7**	**5**	**7**	**8**	**8**	**6**	**6**	**7**	**5**	**7**	**7**	**8**	**7**	**5**	**5**	**8**	**8**	**6**	**4**	**3**	**6**	**8**

NB. Critical appraisal was conducted for full text publications, due to lack of sufficient data from conference abstracts.

¥ Representativeness of the sample: a star is given if the sample is truly/somewhat representative of HS patients, for the sample size: a star is given if the sample size is justified and satisfactory, for non-respondents, a star is given if there is comparability between respondents and non-respondents' characteristics, and the response rate is satisfactory, a star is given for ascertainment of exposure if a validated measurement tool has been used, or a non-validated tool that is described. For comparability, a star is given if the study controls for the most important factor and another star is given if there is control for other additional factors. For the assessment of outcome, two stars are given if there is independent blind assessment, or record linkage, while one star is given if there is only self-report of the outcome. For the statistical test, one star is given if the statistical test used to analyze the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value).

Figure S2: ***Matrix presenting critical appraisal results of Cohort studies (New-Castle Ottawa Scale)¥***

	Cohort studies								
Items	Cuenca-Barrales, 2021	Caposiena, 2021	Fabbrocini, 2021	Grimstad, 2019	Jorgensen, 2020	Jorgensen, 2021	Van Straalen, 2021	Marzano,2021	McKenzie, 2020
Patient Selection									
Representativeness of exposed cohort	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆
Selection of non-exposed cohort	⋆	⋆		⋆		⋆	⋆		
Ascertainment of exposure	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆
Outcome is not present at baseline			⋆	⋆		⋆	⋆	⋆	
Comparability of cohorts									
Controls for other variables	⋆⋆	⋆		⋆	⋆	⋆⋆	⋆⋆		
Outcome									
Assessment of outcome	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆	⋆
Sufficient follow-up duration			⋆	⋆	⋆	⋆	⋆	⋆	⋆
Lost to follow up unlikely to introduce bias		⋆	⋆	⋆	⋆	⋆		⋆	⋆
Total Score	**6**	**6**	**6**	**8**	**6**	**9**	**8**	**6**	**5**

Notes. Critical appraisal was conducted for full text publications, due to lack of sufficient data from conference abstracts.

¥ Representativeness of the exposed cohort: a star is given if the sample is truly/somewhat representative of HS patients, for selection of the non-exposed cohort: a star is given if the non-exposed cohort is drawn from the same community as the exposed cohort, for ascertainment of exposure: a star is given if a secure record or structured interview is used. A star is given also if there is demonstration that outcome of interest was not present at start of study. For Comparability of cohorts: a star is given if there is control for the main confounders, and another star is given if there is control for more relevant confounders. For the outcomes: a star is given if there is independent assessment of the outcome or record linkage, a star is given if follow up is long enough for outcomes to occur, a star is given if there is complete for all subjects, or if subjects lost to follow up unlikely to introduce bias- number lost less than or equal to 20% or description of those lost suggested no different from those followed.

*For the assessment of exposure, in **Cuenca-Barrales 2021** exposure is, per authors' objective, is being diagnosed as HS with inflammatory phenotype (IP) and the non-exposed would be non-inflammatory (IP was hypothesized to be associated with more severe disease and greater impairment of QoL). For **Caposiena 2021**, all patients were taking ADA, the exposure here would be the characteristics that the authors hypothesized to be risk factors for development of the outcome (flares).In **Jorgensen 2021**, authors assessed different treatment regimens (tetracycline, doxycycline, or lymecycline), and the outcomes were QoL of the patients, so exposed and non-exposed would refer to the different treatments, and since authors adjusted for many relevant variables, the study is given 2 stars for the comparability of cohorts. **Jorgensen 2020**, a prospective cohort that assessed factors affecting QoL in patients with HS, a star was given to the comparability of cohorts, as authors adjusted for and stratified by possible factors that might bias the results, considering the cohorts here to be various categories of HS patients with DM vs non diabetics, severe disease vs mild disease, obese vs non obese, etc. **Van Straalen 2021** exposed and non-exposed refer to the different groups exposed to different treatments, as the objective of the authors was to assess the 12-week effectiveness of oral tetracyclines and a combination of clindamycin and rifampicin.*

Figure S3: ***Matrix presenting critical appraisal results of Case-control (New-Castle Ottawa Scale) ¥***

Case-control studies				
Items	Aarts, 2021	Andersen, 2020	Kaaz, 2018	Onderdijk, 2013
Patient Selection				
Adequate case definition	⋆	⋆	⋆	⋆
Representativeness of the cases	⋆	⋆	⋆	⋆
Selection of Controls	⋆	⋆	⋆	
Definition of controls	⋆	⋆	⋆	⋆
Comparability				
Cases and control comparable	⋆⋆	⋆	⋆	⋆⋆
Exposure				
Assessment of exposure	⋆	⋆	⋆	⋆
Same method of ascertainment for cases & controls	⋆	⋆	⋆	⋆
Non-Response rate				⋆
Total score	**8**	**7**	**7**	**8**

¥ Adequate case definition: a star is given if the case is adequately defined, representativeness of the cases: a star is given if there is consecutive or obviously representative series of cases, for selection of controls: a star is given if the controls are community controls, for the definition of controls: a star is given if there is no history of the disease, for comparability: a star is given if the study controls for the most important factors, for ascertainment of exposure: a star is given either if the exposure is from a secure record or structured interview. Also, another star is given if the same methos of ascertainment of exposure is used for both cases and controls, for the non-response rate: a star is given if it is the same for both cases and controls.

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