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PATIENT PAGE

Unmet clinical needs, burden of disease and treatment patterns in hidradenitis suppurativa: Real-world experience from Spain

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Abstract

Background: Hidradenitis suppurativa (HS) is a chronic, inflammatory, debilitating skin disease. HS is difficult-to-treat, and a multifaceted treatment approach is recommended to achieve adequate clinical response. A greater understanding of HS treatment could help identify unmet clinical needs.

Objectives: To evaluate disease characteristics and treatment patterns in a real-world population of patients with HS in Spain.

Methods: This retrospective analysis utilised data collected from the Adelphi HS Disease Specific Programme between November 2020 and April 2021. Dermatologists completed patient record forms (PRFs) for consulting HS patients. Outcomes included disease severity, HS clinical signs, quality of life measures, medical treatments and previous surgeries.

Results: Overall, 53 dermatologists completed 332 PRFs, each representing one patient with HS. Based on physician-judged disease severity at sampling, 73.8%, 22.9% and 3.3% of patients were classified as mild, moderate or severe, respectively. Overall, patients presented with 2.8±2.7 (mean±SD) HS symptoms, which increased with worsening disease severity. The most frequently reported symptoms were 'inflammation/redness of HS lesions/abscess' (45.9%), general pain/discomfort (39.9%) and pain on sitting (32.3%). Overall, patients reported a mean±SD Dermatology Life Quality Index score of 4.7±4.8, which increased with worsening disease severity (mild, 3.9±4.3; moderate, 8.7±5.1; moderate to severe, 9.0±5.1). When asked what effect HS had on everyday activities, a large proportion of patients reported that HS sometimes or greatly affected personal appearance/self-confidence (66.0%), mood (60.2%), close personal relationships (60.4%), motivation (38.3%), leisure activities (43.0%) and feelings about the future (33.6%). At the time of HS diagnosis, the most frequently prescribed treatment regimens were topicals

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(70.7%), antibiotics (57.6%) and antiseptics (32.2%). At the time of sampling, the most common treatment regimens were biologics (43.8%), topicals (34.9%) and antibiotics (32.2%). The mean±SD number of surgical interventions was 0.6±0.8; incision and drainage (31.3%), local or limited excision (13.0%), and wide surgical excision of all hair-bearing skin (9.9%) were the most common surgeries.

Conclusions: These real-world data suggest a high disease burden in patients with HS in Spain. Patients received multiple treatments, and a notable proportion underwent surgery. More data are needed to define optimal HS management strategies.

KEYWORDS

biologics; disease burden; epidemiology; hidradenitis suppurativa; quality of life; therapeutics; treatment, diagnosis; unmet needs

INTRODUCTION

Hidradenitis suppurativa (HS) is a chronic, recurrent, inflammatory, follicular skin disease characterised by deep dermal inflammatory nodules and abscesses, which are typically located in the apocrine gland-bearing skin of the axillary, inguinal and anogenital regions.[1–3] HS is a common skin disorder, for which the average reported prevalence in Europe is approximately 1%.[4,5] A Spanish study reported that the prevalence of adolescent-onset HS (between 10 and 21 years old) was 51.5%.[6] Diagnostic delay is frequent in HS and is reported to be between 7 and 10 years from onset of disease to diagnosis.[7,8] This is concerning because a delay in HS diagnosis can lead to disease progression and concomitant systemic disorders.[9,10]

Patients with HS experience a high disease burden; chronic and intense pain, pruritus, scarring and malodorous discharge are common symptoms, which can lead to embarrassment, depression and social stigma, ultimately impacting patient quality of life (QoL).[9,11–14] In addition, HS is associated with comorbidities that include axial spondylarthritis, inflammatory bowel disease and metabolic syndrome, as well as increased risk of cardiovascular disease.[2,11,15,16] Further, HS is associated with a substantial economic burden that includes direct healthcare costs, loss of work and slow income growth.[17,18] For example, a study conducted in Catalonia in Spain reported that health resource consumption per capita in 2017 was higher in patients with HS (€1520.8) than in patients without HS (€994.7).[19]

HS is challenging to treat and requires an early, multifaceted, multidisciplinary approach to achieve an adequate response.[20] Treatment for HS typically includes a combination of anti-inflammatory and antimicrobial treatments and surgical intervention.[4,21,22] At present, adalimumab is the only approved biologic treatment for moderate to severe HS and has demonstrated good efficacy and a favourable safety profile.[22] Secukinumab has been recently demonstrated to be efficacious with a favourable safety profile for the treatment of patients with moderate to severe HS in two phase 3 clinical trials.[23]

A 2022 study by Ingram et al. reported on the disease characteristics, disease severity and impact of HS on patient QoL in a real-world population of patients with HS across six countries.[9] This study further builds on the findings reported by Ingram et al.,[9] and aims to describe the clinical unmet need, disease characteristics and treatment patterns in a real-world HS population from Spain.

METHODS

Study design

The study design and data source from the wider global study have been reported previously.[9] Briefly, this was a retrospective analysis of a cross-sectional, point-in-time, market research survey utilising data collected independently of Novartis from the Adelphi HS Disease Specific Programme (DSP™) in the United States and five key European countries (EU5; France, Germany, Italy, Spain and the United Kingdom) from November 2020 to April 2021. Here we report on data collected from Spain only. The survey comprised a combination of physician-reported data and physician-completed medical record–extracted data,

TABLE 1 Study population demographics overall and based on physician-judged severity at the time of sampling.

		Physician-judged severity at the time of sampling			
Characteristic	**Overall (*N* = 332)**	**Mild (*N* = 245)**	**Moderate (*N* = 76)**	**Severe (*N* = 11)**	**Moderate to severe (*N* = 87)**
Age, mean ± SD	35.8 ± 12.0	35.0 ± 11.4	37.4 ± 13.3	43.0 ± 13.8	38.1 ± 13.4
Sex, female, *n* (%)	166 (50.0)	133 (54.3)	31 (40.8)	2 (18.2)	33 (37.9)
Ethnicity, *n* (%)					
White	301 (90.7)	223 (91.0)	67 (88.2)	11 (100.0)	78 (89.7)
Hispanic/Latino	29 (8.7)	20 (8.2)	9 (11.8)	0 (0.0)	9 (10.3)
Afro-Caribbean	2 (0.6)	2 (0.8)	0 (0.0)	0 (0.0)	0 (0.0)
Weight, kg, mean ± SD	78.8 ± 15.6	77.6 ± 15.7	80.6 ± 13.6	93.8 ± 19.6	82.3 ± 15.0
BMI, kg/m^2, mean ± SD	27.3 ± 4.6	27.0 ± 4.6	27.8 ± 4.3	30.7 ± 6.2	28.1 ± 4.6
Smoking status, *n* (%)	*N* = 294	*N* = 216	*N* = 67	*N* = 11	*N* = 78
Current smoker	131 (44.6)	95 (44.0)	29 (43.3)	7 (63.6)	36 (46.1)
Ex-smoker	73 (24.8)	50 (23.1)	23 (34.3)	0 (0.0)	23 (29.5)
Never smoked	90 (30.6)	71 (32.9)	15 (22.4)	4 (36.4)	19 (24.4)
Currently in remission, yes, *n* (%)	205 (62.3) (*N* = 329)	184 (75.4) (*N* = 244)	18 (24.3) (*N* = 74)	3 (27.3) (*N* = 11)	21 (24.7) (*N* = 85)
Hurley staging, *n* (%)					
Hurley I	165 (49.7)	155 (63.3)	10 (13.1)	0 (0.0)	10 (11.5)
Hurley II	131 (39.5)	80 (32.6)	49 (64.5)	2 (18.2)	51 (58.6)
Hurley III	36 (10.8)	10 (4.1)	17 (22.4)	9 (81.8)	26 (29.9)
Time since first physician consultation about HS symptoms, years, mean ± SD	6.8 ± 6.3 (*N* = 218)	6.8 ± 6.6 (*N* = 157)	6.3 ± 5.1 (*N* = 54)	9.4 ± 7.9 (*N* = 7)	6.6 ± 5.5 (*N* = 61)
Time since HS diagnosis, years, mean ± SD	4.9 ± 5.0 (*N* = 258)	5.0 ± 5.2 (*N* = 185)	4.3 ± 4.4 (*N* = 64)	7.2 ± 5.5 (*N* = 9)	4.6 ± 4.6 (*N* = 73)

Abbreviations: BMI, body mass index; HS, hidradenitis suppurativa; *n*, number of patients with outcome; *N*, number of patients with available data; SD, standard deviation.

and patient data. Eligible physicians were dermatologists who had consulted with ≥2 patients with HS in the previous 12 months; eligible patients had a diagnosis of HS at data collection. Additional information on the inclusion and exclusion criteria, data sources, ethical considerations and data analyses are detailed in the Supporting Information.

HS disease severity

HS disease severity was physician-judged, with no clinical definition applied, and was classified as mild, moderate and severe. Physicians, therefore, may have subjectively incorporated multiple factors to evaluate disease severity including QoL, symptomology, Hurley staging and other clinical signs. Despite subjectively judging disease severity, a previous study reported that physician-judged severity closely aligned with Hurley stage in a global population of physicians.[9]

Study objectives and outcomes

The overarching objectives of this study were to describe physician- and patient-reported clinical unmet needs, disease characteristics and treatment patterns among the general HS patient population in Spain. The study outcome measures reported in the current manuscript include the following: Physician-judged disease severity (mild, moderate and severe) at the time of diagnosis (retrospectively assessed; termed 'at diagnosis') and at the time of data collection (termed 'at sampling'); number and types of HS clinical signs

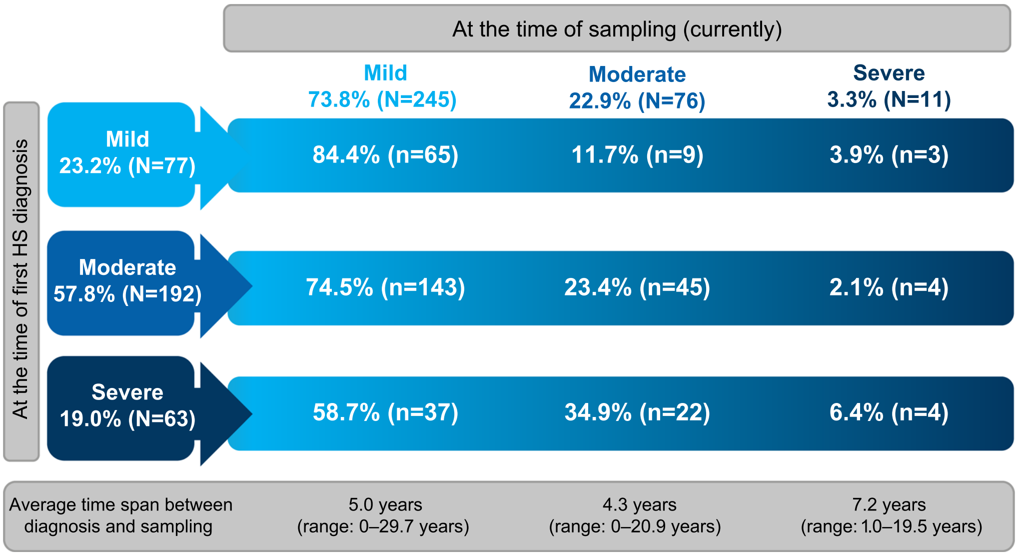


FIGURE 1 Physician-judged disease severity retrospectively at the time of diagnosis versus at the time of sampling. Disease severity (mild, moderate and severe) at the time of diagnosis and the time of sampling. HS, hidradenitis suppurativa; *n*, number of patients with outcome; *N*, number of patients with available data.

including abscesses, inflammatory nodules, draining tunnels and scarring at diagnosis and at sampling; HS-specific symptoms and anatomical areas affected; patient QoL and patient-reported outcome measures; medical treatments at diagnosis and at sampling, and medical treatments ever received (e.g. treatment class, individual brand); treatment patterns throughout order of therapy; flare status and treatments prescribed in response to a flare, where applicable; previous surgical treatments.

RESULTS

Demographic and clinical characteristics

Data were obtained from 53 physicians, which represented a total of 332 patients with HS from Spain. Patient-reported data were collected from 33.1% (110/332) of patients via the patient self-completion form. In the overall cohort of patients ($N = 332$), the mean ± SD age was 35.8 ± 12.0 years, 50.0% of patients were female and most patients (90.7%) were White. Additional patient demographics and disease characteristics are detailed in Table 1.

At the time of sampling, physicians classified 73.8% (245/332), 22.9% (76/332) and 3.3% (11/332) of patients as having mild, moderate and severe disease severity, respectively. Alongside HS, patients presented with several co-morbidities, as reported by physicians, including acne (33.4%, 111/332), obesity (22.6%, 75/332), anxiety (15.4%, 51/332), depression (10.2%, 34/332) and dyslipidaemia (9.3%, 31/332).

Statins (11.4%, 38/332), antidepressants (9.3%, 31/332), angiotensin-converting enzyme inhibitors (5.1%, 17/332) and noninsulin antidiabetics (4.2%, 14/332) were the most frequently prescribed concomitant medications.

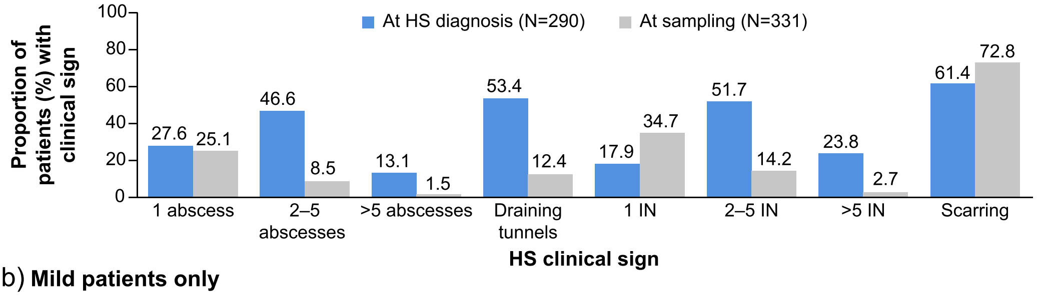
HS disease severity over time

By using physician-judged disease severity retrospectively at the time of HS diagnosis and the time of sampling, the patient clinical unmet need could be determined (Figure 1). For patients with physician-judged mild disease at diagnosis (23.2%), 11.7% progressed to moderate disease at sampling and 3.9% progressed to severe disease at sampling (Figure 1). For patients with physician-judged moderate disease at diagnosis (57.8%), 23.4% remained with moderate disease at sampling and 2.1% progressed to severe disease at sampling. For patients with physician-judged severe disease at diagnosis (19.0%), 34.9% still had moderate disease at sampling and 6.4% remained with severe disease at sampling.

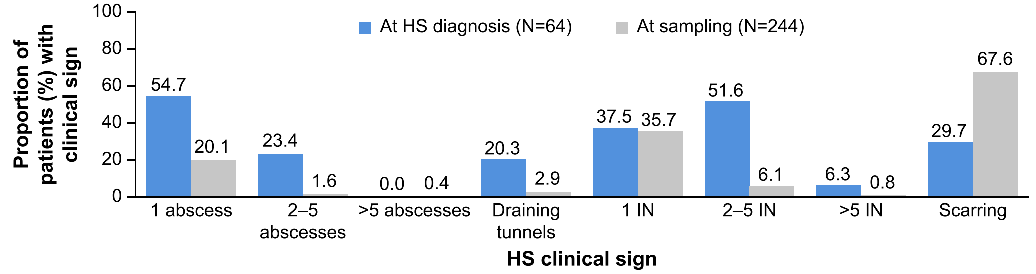
HS clinical signs over time

Based on physician-judged severity retrospectively at the time of diagnosis and at the time of sampling, clinical signs over time and the effects of receiving a

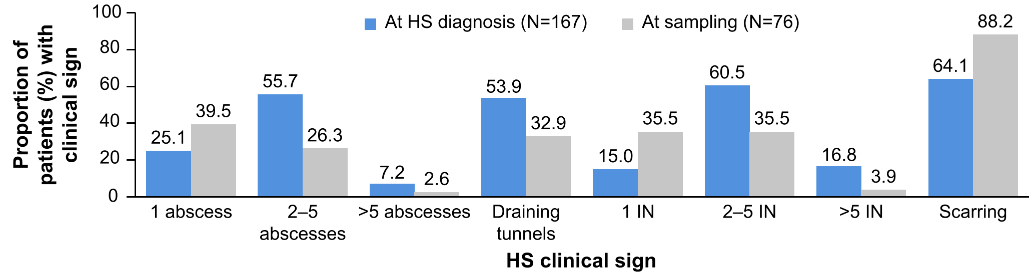
(a) **Overall patients**



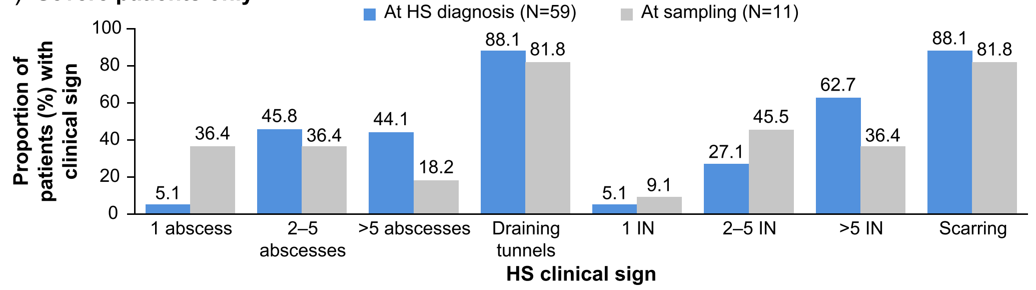
(b) **Mild patients only**



(c) **Moderate patients only**



(d) **Severe patients only**



(e) **Moderate to severe patients only**

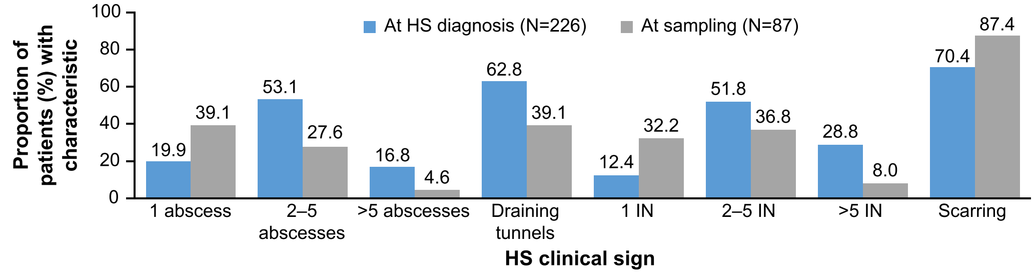


FIGURE 2 HS clinical signs at the time of HS diagnosis and at the time of sampling (a) overall and in (b) mild patients only; (c) moderate patients only; (d) severe patients only; (e) moderate to severe patients only. HS, hidradenitis suppurativa; IN, inflammatory nodule; *N*, number of patients with available data.

TABLE 2 Frequency of symptoms present and areas affected overall and based on physician-judged severity at the time of sampling.

		Physician-judged severity at the time of sampling			
Characteristic	**Overall (*N* = 332)**	**Mild (*N* = 245)**	**Moderate (*N* = 76)**	**Severe (*N* = 11)**	**Moderate to severe (*N* = 87)**
Number of current symptoms, mean ± SD	2.8 ± 2.7	2.2 ± 2.2	4.6 ± 3.2	5.1 ± 2.6	4.6 ± 3.1
Most common[a] current HS symptoms, *n* (%)	(*N* = 331)	(*N* = 245)	(*N* = 75)	(*N* = 11)	(*N* = 86)
Inflammation/redness of HS lesions/abscesses	152 (45.9)	94 (38.4)	48 (64.0)	10 (90.9)	58 (67.4)
General pain/discomfort	132 (39.9)	80 (32.7)	45 (60.0)	7 (63.6)	52 (60.5)
Pain on sitting	107 (32.3)	59 (24.1)	41 (54.7)	7 (63.6)	48 (55.8)
Drainage from HS lesions/abscesses	105 (31.7)	53 (21.6)	46 (61.3)	6 (54.5)	52 (60.5)
Itching	91 (27.5)	64 (26.1)	23 (30.7)	4 (36.4)	27 (31.4)
Restricted/painful movement of arms/legs	90 (27.2)	50 (20.4)	35 (46.7)	5 (45.5)	40 (46.5)
Malodorous drainage	64 (19.3)	34 (13.9)	25 (33.3)	5 (45.5)	30 (34.9)
Low mood/depression	58 (17.5)	31 (12.7)	20 (26.7)	7 (63.6)	27 (31.4)
Infection of HS lesions/abscesses	57 (17.2)	32 (13.1)	22 (29.3)	3 (27.3)	25 (29.1)
Sleep disturbance	38 (11.5)	15 (6.1)	22 (29.3)	1 (9.1)	23 (26.7)
Number of current areas affected, mean ± SD	2.6 ± 1.7	2.3 ± 1.5	3.4 ± 1.8	4.2 ± 2.0	3.5 ± 1.9
Most common[a] anatomical areas currently affected, *n* (%)					
Armpits	211 (63.6)	155 (63.3)	48 (63.2)	8 (72.7)	56 (64.4)
Groin	196 (59.0)	134 (54.7)	55 (72.4)	7 (63.6)	62 (71.3)
Buttocks	131 (39.5)	83 (33.9)	42 (55.3)	6 (54.5)	48 (55.2)
Genitals or pubic region	80 (24.1)	43 (17.6)	31 (40.8)	6 (54.5)	37 (42.5)
Anus and perianal skin	73 (22.0)	35 (14.3)	33 (43.4)	5 (45.5)	38 (43.7)
Breast and chest	50 (15.1)	36 (14.7)	11 (14.5)	3 (27.3)	14 (16.1)
Inner thighs	47 (14.2)	30 (12.2)	14 (18.4)	3 (27.3)	17 (19.5)
Abdomen	23 (6.9)	13 (5.3)	8 (10.5)	2 (18.2)	10 (11.5)
Back	20 (6.0)	14 (5.7)	4 (5.3)	2 (18.2)	6 (6.9)
Face	16 (4.8)	11 (4.5)	5 (6.6)	0 (0.0)	5 (5.7)

Abbreviations: HS, hidradenitis suppurativa; n, number of patients with outcome; N, number of patients with available data; SD, standard deviation.

[a] Only the 10 most frequently experienced symptoms or areas affected are detailed. Patients may have presented with multiple symptoms and multiple affected areas.

delayed HS diagnosis on clinical signs could be determined (Figure 2). Clinical signs greatly improved at the time of sampling in patients with a mild diagnosis, which was particularly evident for patients with 2–5 abscesses (diagnosis, 23.4%; sampling, 1.6%), 2–5 inflammatory nodules (diagnosis, 51.6%; sampling, 6.1%) and draining tunnels (diagnosis, 20.3%; sampling, 2.9%) (Figure 2b). In contrast, for patients diagnosed with moderate or severe disease, clinical signs were similar for those with a moderate or severe diagnosis at the time of sampling. This was particularly evident for patients with draining tunnels (moderate at diagnosis, 53.9%; moderate at sampling, 32.9%; severe at diagnosis, 88.1%; severe at sampling, 81.8%) (Figure 2c,d).

Current HS symptoms and areas affected

Despite most patients receiving treatment for their HS, patients still presented with multiple HS symptoms in multiple anatomical areas at the time of sampling (Table 2), with symptoms such as pain on sitting, malodorous drainage and low mood/depression being more common with worsening disease severity.

The most common anatomical areas affected were the armpits, groin and buttocks. Patients presented with 2.8 ± 2.7 (mean ± SD) symptoms, which increased with greater disease severity. Furthermore, patients were affected in 2.6 ± 1.7 (mean ± SD) anatomical areas, which increased with greater disease severity.

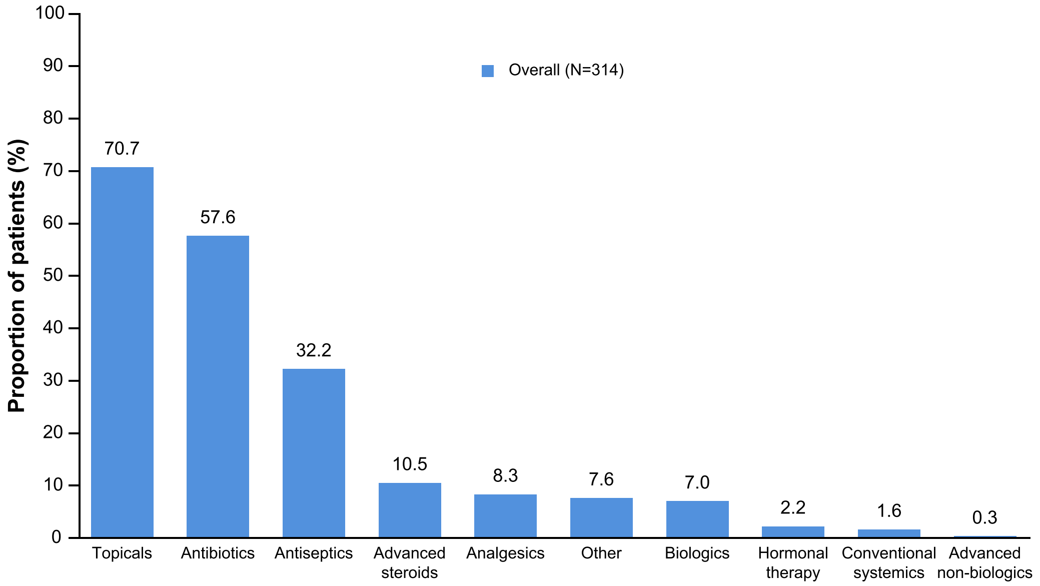
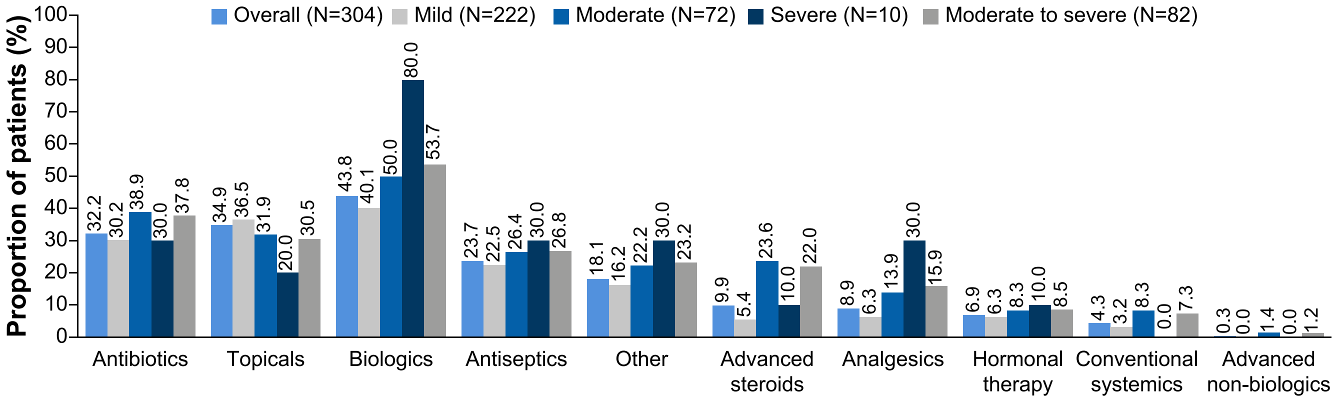


FIGURE 3 Prescribed treatment classes at the time of HS diagnosis. 'Other' encompasses oral antidiabetics and retinoids, 'advanced steroids' encompasses oral corticosteroids or corticosteroid injections and 'advanced non-biologics' encompasses apremilast, tofacitinib and baricitinib. *N*, number of patients with available data.

(a) **Current treatment classes**



(b) **Treatment classes ever prescribed**

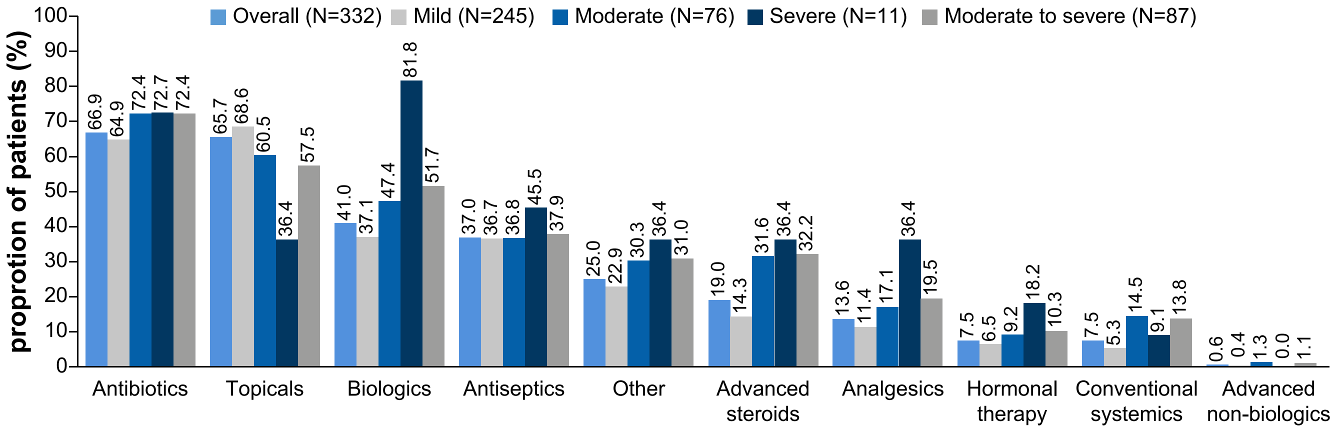


FIGURE 4 Treatment classes prescribed overall and based on physician-judged severity at the time of sampling for (a) current treatment classes and (b) treatment classes ever prescribed. 'Other' encompasses oral antidiabetics and retinoids, 'advanced steroids' encompasses oral corticosteroids or corticosteroid injections and 'advanced non-biologics' encompasses apremilast, tofacitinib and baricitinib. *N*, number of patients with available data.

Effects of HS on QoL

The effect of HS on patient QoL was substantial in this cohort of patients (Supporting Information: Figure S1). Patients reported a mean ± SD Dermatology Life Quality Index (DLQI) score of 4.7 ± 4.8, which increased with worsening disease severity (mild, 3.9 ± 4.3; moderate, 8.7 ± 5.1; moderate to severe, 9.0 ± 5.1; Supporting Information: Figure S1A), and a mean ± SD Hidradenitis Suppurativa Quality of Life score of 9.8 ± 10.2, which increased with worsening disease severity (mild, 8.2 ± 8.8; moderate, 18.1 ± 11.8; moderate to severe, 19.5 ± 12.6; Supporting Information: Figure S1C), indicating a worse QoL. Although QoL was worse in patients with more severe disease, only 35.5% of patients with mild disease reported that HS had no effect at all on their life (DLQI 0–1; Supporting Information: Figure S1B). The work productivity and activity impairment assessment showed an overall work impairment of 12.5% due to HS, which was greater in patients with more severe disease (mild, 10.9%; moderate, 23.5%; moderate to severe, 23.5%; Supporting Information: Figure S1D).

In addition to these assessments, patients were also asked to report on the effects HS had on several everyday activities on a four-point Likert scale (no effect, rarely affected, sometimes affected and greatly affected) (Supporting Information: Figure S2). Overall, several everyday activities were sometimes or greatly affected in patients with HS including personal appearance/self-confidence (66.0%; Supporting Information: Figure S2A), mood (60.2%; Supporting Information: Figure S2B), close personal relationships (60.4%; Supporting Information: Figure S2C), motivation (38.3%; Supporting Information: Figure S2D), leisure activities (43.0%; Supporting Information: Figure S2E) and feelings about the future (33.6%; Supporting Information: Figure S2F). Generally, as disease severity worsened, the proportion of patients reporting that HS had sometimes/greatly affected their everyday activities increased (Supporting Information: Figure S2).

Medical treatments at diagnosis

At the time of diagnosis, the most frequently prescribed treatment regimens were topicals (70.7%), antibiotics (57.6%) and antiseptics (32.2%) (Figure 3). Overall, 5.4% (18/332) of patients were not on any treatment at the time of diagnosis. Despite a large proportion of patients being classified as having moderate to severe HS at diagnosis (76.8% [255/332]), only 7.0% (22/314) and 1.6% (5/314) of patients were prescribed biologics and conventional systemics, respectively (Figure 3).

Current treatment patterns and treatments ever received

At the time of sampling, the most common treatment regimens were biologics (43.8%), topicals (34.9%) and antibiotics (32.2%) (Figure 4a). Further, at the time of sampling, 8.4% (28/332) of patients were not on any treatment. Patients with severe HS disease were prescribed biologics (80.0%) and analgesics (30.0%) more often than those with moderate (biologics, 50.0%; analgesics, 13.9%) or mild disease (biologics, 40.1%; analgesics, 6.3%), whereas patients with severe HS disease were prescribed topicals less frequently than those with other severities (20.0%) (Figure 4a). For treatment regimens that patients had ever received, antibiotics (66.9%), topicals (65.7%) and biologics (41.0%) were the most frequent treatment regimens (Figure 4b). Most patients with severe HS disease had received biologics at some point in their disease management (81.8%).

Treatment patterns through order of therapy

The classes of treatment regimens prescribed throughout the order of therapy were assessed to illustrate treatment regimen timelines (Supporting Information: Table S1). Overall, topicals (67.6%) and antibiotics (59.3%) were the most prescribed as a first-line treatment for HS, whereas biologics (18.9%) and conventional systemics (4.5%) had relatively lower prescription rates, even for patients with severe HS disease (biologics, 36.4%; conventional systemics, 9.1%). As treatment lines progressed to fourth or later treatment lines, the proportion of patients being prescribed topicals (27.3%) declined, whereas the proportion of patients being prescribed biologics (63.6%) increased, with 100.0% of patients with severe disease prescribed biologics by the fourth or later treatment lines; the proportion of patients prescribed antibiotics (50.0%) and conventional systemics (4.5%) by the fourth or later treatment lines remained relatively unchanged.

HS flares

A large proportion (74.7%) of patients experienced flares immediately before the initiation of their current treatment (Supporting Information: Figure S3A). Among the patients who experienced flares, the treatment approach in 94.9% of patients was in response to the patient's flare (Supporting Information: Figure S3B). The most common treatment regimens in response to a flare were antibiotics (46.2%), topicals (40.0%) and biologics (39.2%), with biologics being more commonly prescribed in patients with severe disease (60.0%) than in patients with moderate (31.4%) or mild (41.1%) disease (Supporting Information: Figure S3C).

Surgical treatment

Overall, patients underwent 0.6 ± 0.8 (mean ± SD) surgeries, of which incision and drainage (31.3%, 104/332), local or limited excision (13.0%, 43/332), and wide surgical excision of all hair-bearing skin (9.9%, 33/332) were the most common. Patients with severe disease underwent 1.4 ± 0.7 (mean ± SD) surgeries, with a greater proportion of patients undergoing incision and drainage (63.6%, 7/11) and local or limited excision (27.3%, 3/11) than patients with moderate (incision and drainage, 44.7% [34/76]; local or limited excision, 14.5% [11/76]) or mild (incision and drainage, 25.7% [63/245]; local or limited excision, 11.8% [29/245]) disease.

Barriers to biologics

A total of 20.2% of patients who were not currently taking a biologic warranted the use of one (Supporting Information: Figure S4); this proportion increased with worsening disease severity. Of the patients overall who warranted the use of a biologic, the most common reasons physicians provided for patients not being prescribed one were 'I prefer to exhaust all other treatment options first' (57.5%, 23/40), 'patient in remission' (22.5%, 9/40) and 'very recent diagnosis' (17.5%, 7/40) (Supporting Information: Table S2).

DISCUSSION

Owing to the heterogeneous presentation of HS, selecting an appropriate treatment management strategy may vary from patient to patient. We found that patients with HS in Spain experienced a substantial disease burden. Patients received a variety of treatments to manage their condition, of which the most frequently prescribed at diagnosis was topicals. A small proportion of patients were prescribed biologics or conventional systemics at diagnosis. Incision and drainage were the most frequent surgical interventions.

In the current study, physician-judged severity at the time of the first HS diagnosis in Spain was classified as moderate in 57.8% and severe in 19.0% of patients. These findings are consistent with the previous global study, which reported that the proportion of patients with moderate disease at the time of the first diagnosis was 53.7% and with severe disease was 19.9%.[9] These findings suggest that there may be a delay in diagnosis, which could be due to a lack of knowledge of the disease in society and among primary care physicians, no referral to dermatologists, and the fact that patients may visit the emergency department rather than dermatologists. Further, a delay in diagnosis can occur despite diagnosis being based on clinical factors such as lesion type, location and recurrence. Of note is that ultrasound can detect subclinical disease and can thereby modify the clinical staging and therapeutic management in HS.[24]

We found that, in general, in patients receiving a diagnosis of HS with a more advanced disease severity (e.g. moderate or severe), the frequency of severe HS clinical signs remained relatively unchanged or had worsened by the time of sampling. These findings suggest progression of disease and highlight the importance of early treatment for HS for improved patient outcomes. Previous reports have alluded to a 'window of opportunity' hypothesis in HS in relation to the early use of adalimumab for the treatment of moderate to severe HS, where therapeutic delay (time from onset of HS to initiation of adalimumab) significantly correlated to a lack of clinical response.[25]

At the time of diagnosis, the most frequently prescribed treatment regimens were topicals and antibiotics. These results align with European S1 HS treatment guideline recommendations.[4] At the time of sampling, the most common treatment regimens in the current study were biologics and topicals. This may be indicative of a willingness of physicians in Spain to prescribe biologics for HS and access to biological treatments, including the health systems and adherence to guideline recommendations. Currently, adalimumab is the only approved biologic in HS.[26]

Patients underwent an average of 0.6 surgeries, of which incision and drainage, local or limited excision and wide surgical excision of all hair-bearing skin were the most frequent. A 2020 Spanish study reported that among 104 patients with HS, deroofing was the most frequent surgical technique used (in 48% of patients), followed by wide excision with direct closure (33.3%) and wide excision with flap or graft reconstruction (10.4%).[27] This difference could be due to different patient populations or a lack of consensus on the surgical approach for HS.

Limitations of this study include the use of a subjective, physician-judged severity assessment.

Further, the accuracy of survey-based data is dependent on the quality of data collection, which may be subject to recall bias. Selection bias may have influenced the selection of patients and physicians included in this survey. The sample size was relatively small so results should be interpreted with caution. This survey is cross-sectional in nature and cannot be used to demonstrate cause and effect. A further consideration is that this survey was conducted during the Coronavirus (COVID-19) pandemic; as a result, a large proportion of consultations occurred virtually, which may have biased clinical and severity assessments.

CONCLUSIONS

This real-world survey in patients with HS from Spain demonstrates that there is a high disease burden in patients with HS and a significant impact on patients' lives. Furthermore, the study reveals that disease burden is poorly managed in patients with HS and leads to flares and disease progression over time. This is particularly evident in patients with moderate to severe disease. These data highlight the need to reduce the time to first diagnosis and the lack of availability of therapeutic options to control the symptoms of HS.

AUTHOR CONTRIBUTIONS

Eva Vilarrasa, Alejandro Molina-Leyva, Víctor Martín, Emily Coak, Isabel Truman, Hayley Wallinger, Craig Richardson and Antonio Martorell made substantial contributions to the conception and design, acquisition of data or analysis and interpretation of data. All authors drafted the article or revised it critically for important intellectual content, approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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CONFLICTS OF INTEREST STATEMENT

Eva Vilarrasa has received consultancy/speaker's honoraria and/or travel grants and/or participated in clinical trials sponsored by AbbVie, Almirall, Amgen, Boehringer Ingelheim, Celgene, Gebro, Isdin, Janssen, LEO Pharma, Lilly, Merck-Serono, MSD, Novartis, Pfizer, Roche, Sandoz, Sanofi and UCB. Alejandro Molina-Leyva has received consultancy/speaker's honoraria and/or travel grants and/or participated in clinical trials sponsored by AbbVie, Almirall, Amgen, Boehringer Ingelheim, Celgene, Gebro, Janssen, LEO Pharma, Lilly, Novartis, Pfizer, Sandoz, Sanofi and UCB. Victor Martín was employed by Novartis Farmacéutica S.A, Madrid, Spain at the time of the study. Emily Coak, Isabel Truman and Hayley Wallinger are employed by Adelphi Real World, Bollington, United Kingdom. Craig Richardson was employed by Novartis Pharma AG, Basel, Switzerland at the time of the study. Antonio Martorell has received consultancy/speaker's honoraria and/or travel grants and/or participated in clinical trials sponsored by AbbVie, Almirall, Amgen, Boehringer Ingelheim, Celgene, Gebro, Janssen, LEO Pharma, Lilly, Novartis, Pfizer, Sandoz, Sanofi and UCB.

DATA AVAILABILITY STATEMENT

Data collection was undertaken by Adelphi Real World as part of an independent survey, entitled the Hidradenitis Suppurativa Disease Specific Programme (DSP™), subscribed to by multiple pharmaceutical companies, of which, one was Novartis Pharma AG. Novartis Pharma AG did not influence the original survey through either contribution to the design of questionnaires or data collection. All data that support the findings of this study are the intellectual property of Adelphi Real World. All requests for access should be addressed directly to Hayley Wallinger at hayley.wallinger@adelphigroup.com.

ETHICS STATEMENT

The survey was performed in compliance with the European Pharmaceutical Market Research Association (EphMRA) guidelines. Ethical approval was obtained from the Western Copernicus Group Institutional Review Board (WCG-IRB).

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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