Dermatology

Research Article

Dermatology
DOI: 10.1159/000542343

Received: August 16, 2023
Accepted: October 19, 2024
Published online: November 5, 2024

Treatment Satisfaction in Patients with Hidradenitis Suppurativa: A Real-World Survey from the EU5 and USA

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Keywords
Hidradenitis suppurativa · Barriers to biologics · Management · Acne inversa · Surgery · Cross-sectional

Abstract

Introduction: Hidradenitis suppurativa (HS) is a debilitating, inflammatory skin disorder. Treatment strategies in patients with HS are challenging; real-world evidence in a HS population is warranted for greater disease understanding. The objective of this analysis was to describe real-world treatment patterns and treatment satisfaction in patients with HS. ***Methods:*** This was a cross-sectional market research survey with retrospective data collection in patients with HS from the USA and five European countries (France, Germany, Italy, Spain, and the UK) between November 2020 and April 2021, using physician- and patient-reported surveys. Eligible physicians were general dermatologists actively managing patients with HS; dermatologists were required to have consulted with ≥2 patients with HS in the previous 12 months. Adult (≥18 years) and adolescent (10–17 years) HS patients visiting a participating dermatologist were included. Outcomes included treatment patterns, flare status, treatments prescribed in response to flares, previous surgeries, barriers to biologics, and patient- and physician-reported satisfaction with the disease control provided by treatment. ***Results:*** Survey data from 1,787 patients were collected from 312 dermatologists. The most

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frequently prescribed treatments were topicals, oral antibiotics, and antiseptic washes/creams at diagnosis and sampling. At sampling, biologics were more frequently prescribed in patients with more severe disease (prescribed in 26.6%, 31.0%, and 52.4% of patients with mild, moderate, and severe disease, respectively); oral antibiotics (48.8%), topicals (37.4%), and biologics (34.3%) were the most frequently prescribed treatment classes in response to a flare. Of patients currently not receiving a biologic, dermatologists reported that 18.9% of patients' condition warranted their use. Approximately one quarter of dermatologists (24.5%) and patients (27.4%) were not satisfied with current treatment; of patients who were dissatisfied, 12.8% reported they would never raise their dissatisfaction with their doctor. ***Conclusion:*** These real-world data suggest a high disease burden and potential undertreatment in patients with HS. Patients received multiple treatments, and a notable proportion underwent surgery. Robustly integrating the patient voice in HS treatment decisions may lead to better outcomes and improved treatment satisfaction.

Introduction

Hidradenitis suppurativa (HS) is a systemic, chronic, debilitating, inflammatory skin condition. It is characterized by painful dermal inflammatory nodules and abscesses, which can cause follicular occlusion and lead to malodorous discharge and draining tunnel formation, resulting in irreversible scarring [1–4]. HS is associated with a high disease burden, and patients can experience significant morbidity and a substantial impact on quality of life (QoL) [2, 3, 5–10]. HS is a relatively common disorder; the exact prevalence is unknown but estimates range between 0.03% and 1.2% in the USA and Europe [5, 11–13]. However, HS may be misdiagnosed or underdiagnosed; an average delay of 7–10 years between symptom onset and HS diagnosis has been reported [14–16]. Diagnostic methods are not clearly defined, with accurate and timely diagnoses relying on the ability of the consulting physician to accurately recognize HS signs and symptoms [15, 17].

HS is a hard-to-treat disease that requires a multifaceted treatment approach. The overall goal of HS treatment is to manage existing lesions while minimizing pain and drainage, decrease the frequency of lesion recurrence, and prevent disease progression and scarring, thereby improving patient QoL [18]. Medical treatments for patients can include topicals, oral antibiotics, retinoids, hormonal therapies, immunosuppressants, and biologic therapies [19, 20], while common surgical procedures include local excisions, deroofing of draining tunnels, and radical wide excision [19–22]. Definitive treatment algorithms for HS are challenging to develop due to the heterogeneity of the disease and complexity of its pathogenesis [23]. Existing treatment algorithms are strongly based on expert opinion and consensus [24], which differ between guidelines, potentially due to regional differences [19–21, 25]. Depending on disease severity, current guidelines recommend a combination of both medical and surgical treatment for HS [18, 20, 21, 26, 27]. However, patient-reported data have indicated that current pain management modalities are only moderately effective at improving pain due to HS [28]. This is relevant because pain is reported as the most troublesome symptom of HS and is associated with the greatest impact on patient QoL [29, 30]. Furthermore, a large proportion of patients report that they are not satisfied with current treatments [16, 31].

Due to the evolving treatment landscape for patients with HS [32] and the challenges to integrate various treatment modalities, current real-world data describing treatment patterns in this population are warranted. This study aimed to describe treatment patterns and satisfaction with treatment in a large, real-world population of patients with HS using physician- and patient-reported data.

Materials and Methods

Study Design

This was a cross-sectional market research survey with retrospective data collection to assess the clinical unmet need, burden of disease, and treatment patterns in patients with HS. We have previously reported on the unmet clinical needs and disease burden in this population including patients from the EU5 (France, Germany, Italy, Spain, and the UK) and the USA [33]. Here, we report on the treatment patterns and treatment satisfaction in patients with HS. Further methods are detailed in the online Supplementary Methods (for all online suppl. material, see https://doi.org/10.1159/000542343) and in Ingram et al. [33].

Data Sources and Questionnaires

All participating physicians were requested to complete a patient record form for the subsequent 5–7 patients with HS attending their practice. The patient record form, which has been previously described [33], consisted

of 11 sections covering multiple topics. Patients were also invited to complete a voluntary self-completion questionnaire relating to their condition; data from physicians and patients were linked at data processing where applicable.

Disease Severity

Disease severity was physician-judged and categorized as mild, moderate, or severe, with no clinical definition applied. Importantly, physician-judged severity was previously reported to be closely aligned with Hurley staging in this patient population [33]. Physician-judged disease severity was recorded retrospectively through chart review at the time of first HS diagnosis and at the time of sampling. The retrospective assessment (severity at first HS diagnosis) was recorded by a physician other than the dermatologist participating in the survey in 47.0% of patients. In these cases, severity was derived from the patient's case notes by the participating physician.

Study Objectives

The primary objective of this manuscript was to evaluate treatment patterns in a large population of patients with HS, with a particular focus on patient and physician satisfaction with treatment and treatment goals overall, and based on physician-judged severity.

Data Analysis

Descriptive statistics were assessed using StataCorp 2019 (Stata Statistical Software: Release 16.1, College Station, TX: StataCorp LLC). Alignment between patient- and physician-reported satisfaction with current disease control was determined using a kappa (κ) statistic. The κ statistic indicates the level of agreement between two outcomes that are measured on the same scale, which ranges from a score of 0 (level of agreement equivalent to chance) to 1 (perfect agreement). Cutoffs for values between 0 and 1 have been previously suggested [34]. Continuous data are reported as mean (standard deviation [SD]) unless otherwise stated; categorical data are presented as a percentage and n/N (n = number of patients with outcome; N = number of patients with available data).

Results

Patient Population and Baseline Characteristics

A full description of the sample population, including the number of patients and physicians included by country, has been previously described [33]. In brief, data from 1,787 patients with HS (EU5, N = 1,305 [73.0%]); USA, N = 482 [27.0%]) were collected by 312 dermatologists (EU5, N = 231 [74.0%]; USA, N = 81 [26.0%]). The mean ± SD age was 34.4 ± 12.2 years, and most patients were female (57.6%, 1,029/1,787) and White (77.7%, 1,388/1,787). Full demographic and disease characteristics have been described previously [33]. At the time of HS diagnosis, 26.4% (472/1,787), 53.7% (959/1,787), and 19.9% (356/1,787) of patients were classified as having mild, moderate, or severe disease, respectively, based on physician-judged severity. At the time of sampling, 66.0% (1,179/1,787), 29.3% (523/1,787), and 4.7% (85/1,787) of patients were classified as having mild, moderate, or severe disease, respectively, based on physician-judged severity. Overall, 142 and 128 patients were not receiving any treatment at the time of diagnosis and sampling, respectively.

Medical Treatment at HS Diagnosis and Current Treatment Patterns

The most prescribed treatments at the time of diagnosis were topicals (59.5%, 978/1,645), oral antibiotics (58.1%, 955/1,645), and antiseptic washes/creams (37.1%, 611/1,645) (online suppl. Figure S1). At the time of sampling, the most prescribed treatments were oral antibiotics (40.3%, 669/1,659), topicals (38.7%, 642/1,659), antiseptic washes/creams (34.0%, 564/1,659), and biologics (29.2%, 484/1,659) (Fig. 1). Patients with severe disease were more frequently receiving biologics at the time of sampling versus patients with mild or moderate disease (Fig. 1). The individual treatments within each treatment class (≥2%) are detailed in online supplementary Table S1.

Barriers to Biologics

Despite currently not receiving biologics, based on physician interpretation, 18.9% (243/1,287) of patients' condition warranted the use of biologics; this was higher with increasing disease severity (mild, 8.5%, 75/882; moderate, 37.5%, 136/363; severe, 76.2%, 32/42). The most common physician-reported reason for not being prescribed a biologic in patients who warranted the use of one (N = 243) was "I prefer to exhaust all other treatment options first" (41.6%, 101/243) (Table 1).

Treatment Satisfaction

Figures describing treatment satisfaction are presented as matched data from physicians and patients together and are represented as overall patients (Fig. 2a), mild patients only (Fig. 2b), moderate patients only (Fig. 2c), and severe patients only (Fig. 2d). Overall, approximately

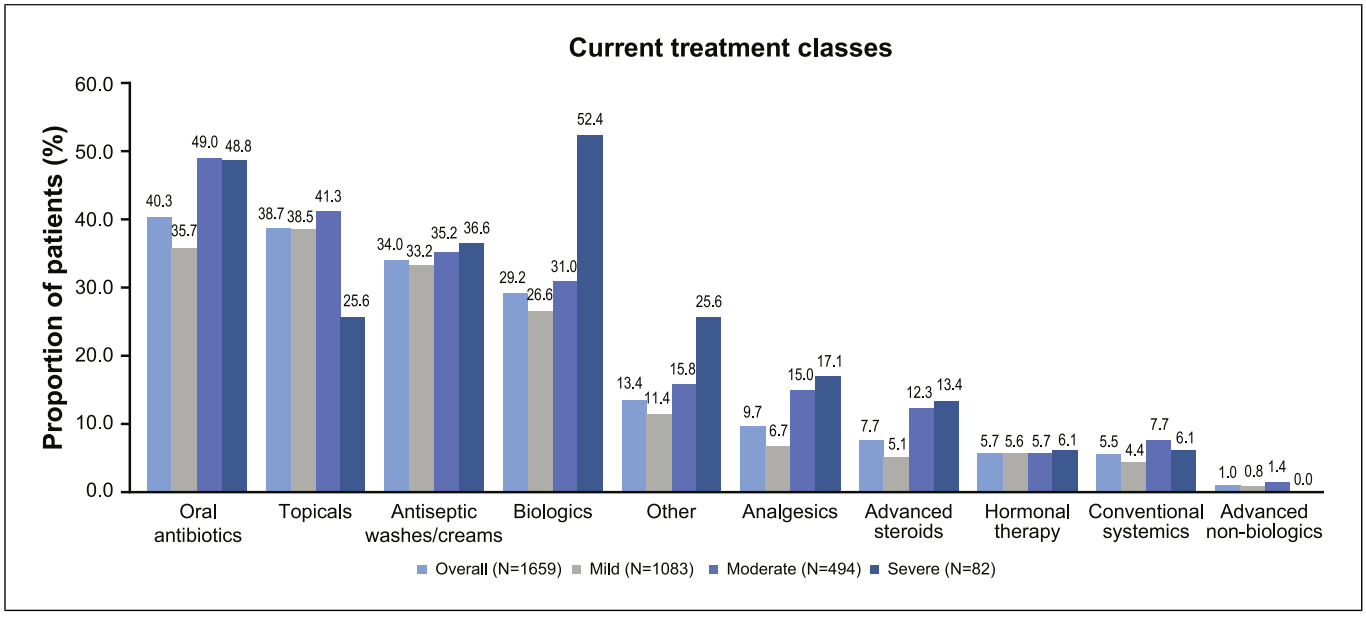

Fig. 1. Current treatment classes prescribed overall and based on physician-judged severity at the time of sampling. Bar graphs illustrating the current treatment classes patients were prescribed at the time of sampling. Patients could be prescribed multiple treatment classes at the same time. "Other" encompasses oral anti-diabetics and retinoids, "advanced steroids" encompasses oral corticosteroids and corticosteroid injections, and "advanced non-biologics" encompasses apremilast, tofacitinib, and baricitinib. *N*, number of patients with available data.

three-quarters of physicians (75.5%, 392/519) and patients (72.6%, 377/519) reported that they were satisfied with the level of HS disease control achieved (Fig. 2a). However, some physicians and patients (physicians: 14.3%, 74/519; patients: 12.3%, 64/519) reported that they were "not satisfied and believe better control can be achieved" (Fig. 2a).

Physician and patient satisfaction with disease control was poor in patients with severe disease; 0.0% (0/15) and 13.3% (2/15) of physicians and patients, respectively, reported that they were "satisfied with the disease control achieved," but 40.0% (6/15) and 46.7% (7/15) of physicians and patients, respectively, reported that they "were not satisfied but believe this is the best disease control that could be realistically achieved" (Fig. 2d). The overall agreement between physician- and patient-reported satisfaction was 78.2% (N = 519), with a Cohen's κ value of 0.4797, indicating a moderate agreement. The most common reason for physician and patient dissatisfaction with disease control overall was "not effective enough at reducing patient's symptoms" (43.3%, 55/127) and "it hasn't helped the HS on certain areas of my body" (30.3%, 43/142), respectively (Table 2).

Overall, most patients (88.3%, 468/530) would recommend their current treatment to a fellow patient with HS; however, this willingness to endorse current treatment was reduced in patients with more severe disease (mild, 95.4% [349/366]; moderate, 74.7% [112/150]; severe, 50.0% [7/14]). Most patients who were satisfied with their current treatment would also recommend it to a fellow patient with HS (97.4%, 376/386). Despite reduced satisfaction levels, over half of patients reported that they would still recommend their current treatment to a fellow patient with HS ("not satisfied, but I believe this is the best control that can be expected for my HS," 68.4% [54/79]; "not satisfied and I believe better control can be achieved," 57.9% [33/57]).

Of the patients who were dissatisfied with current treatment overall, 39.8% (53/133) said that they have not yet but will raise their dissatisfaction with their doctor, while 12.8% (17/133) said that they will never raise their dissatisfaction with their doctor. Additionally, of those who had/would raise it with their doctor, they reported they waited/would wait a mean (SD) time of 3.5 (2.7) months to do so.

Satisfaction with treatment control was also assessed by current treatment with topicals (Fig. 3a), antibiotics (Fig. 3b), conventional systemics (Fig. 3c), and biologics (Fig. 3d). Physicians were most satisfied with the disease control provided by treatment in patients prescribed biologics (82.4%, 103/125), followed by those prescribed topicals (73.9%, 176/238), antibiotics (64.2%, 122/190), and

Table 1. Reasons for patients not receiving a biologic for those whose condition warranted the use of one

Reason	Overall (*N* = 243)	Physician-judged severity at the time of sampling		
		Mild (*N* = 75)	Moderate (*N* = 136)	Severe (*N* = 32)
I prefer to exhaust all other treatment options first	101 (41.6)	34 (45.3)	60 (44.1)	7 (21.9)
Patient dislikes injections/infusions	50 (20.6)	11 (14.7)	33 (24.3)	6 (18.8)
Very recent diagnosis	45 (18.5)	11 (14.7)	26 (19.1)	8 (25.0)
Patient reluctance due to time commitments	31 (12.8)	7 (9.3)	20 (14.7)	4 (12.5)
Other	28 (11.5)	5 (6.7)	17 (12.5)	6 (18.8)
Patient in remission	27 (11.1)	20 (26.7)	6 (4.4)	1 (3.1)
Concerns regarding increased risk of infection	22 (9.1)	7 (9.3)	14 (10.3)	1 (3.1)
Screening required before start of treatment	16 (6.6)	6 (8.0)	6 (4.4)	4 (12.5)
Other safety/side effect concerns	15 (6.2)	4 (5.3)	9 (6.6)	2 (6.3)
Too expensive for patient	12 (4.9)	1 (1.3)	8 (5.9)	3 (9.4)
Unable to secure funding/lack of insurance	12 (4.9)	1 (1.3)	6 (4.4)	5 (15.6)
Concerns regarding malignancy	11 (4.5)	4 (5.3)	6 (4.4)	1 (3.1)
Requirement to obtain prior authorization	10 (4.1)	2 (2.7)	5 (3.7)	3 (9.4)
Formulary restrictions	9 (3.7)	2 (2.7)	5 (3.7)	2 (6.3)
Concerns regarding lack of efficacy	8 (3.3)	3 (4.0)	4 (2.9)	1 (3.1)
Patient does not want to go to an infusion center	7 (2.9)	2 (2.7)	3 (2.2)	2 (6.3)
Childbearing (pregnant/lactating)	7 (2.9)	2 (2.7)	2 (1.5)	3 (9.4)
Biologics are inconvenient/too troublesome to administer	5 (2.1)	2 (2.7)	3 (2.2)	0 (0.0)
A previously prescribed biologic/biosimilar failed	3 (1.2)	1 (1.3)	2 (1.5)	0 (0.0)
Contraindicated	2 (0.8)	0 (0.0)	1 (0.7)	1 (3.1)
Not enough data available	2 (0.8)	0 (0.0)	2 (1.5)	0 (0.0)

Data are presented as *n* (%). "Other" refers to reasons other than those listed in the questionnaire. *n*, number of patients with outcome; *N*, number of patients with available data.

conventional systemics (59.5%, 22/37). Patients prescribed biologics were most satisfied with the disease control provided by their treatment (77.6%, 97/125), followed by those prescribed topicals (71.4%, 170/238), conventional systemics (70.3%, 26/37), and antibiotics (62.1%, 118/190).

Treatment Goals and Attitudes toward Treatment

Physician- and patient-reported treatment goals are detailed in Table 3. Based on matched physician- and patient-reported data overall (N = 522), the most frequently reported treatment goals for physicians were "improves appearance of skin" (57.1%, 298/522), "relieves pain" (54.6%, 285/522), and "works for a long time" (53.8%, 281/522). Similarly, the most frequently reported treatment goals for patients were "improves appearance of my skin" (70.9%, 370/522), "reduces my pain/discomfort" (68.8%, 359/522), and "get rid of the disease" (68.8%, 359/522).

Based on a 1 (completely disagree) to 10 (completely agree) scale, patients ranked several attitudinal statements regarding treatments. Overall, the mean (SD) score for "I am always keen to try the next new treatment for HS and will ask my doctor about anything new" was 6.4 (2.6) (mild, 6.3 [2.7]; moderate, 6.6 [2.2]; severe, 6.5 [2.3]), for "I would change my doctor if I felt he/she was not willing to try new treatments" was 5.2 (3.0) (mild, 4.9 [3.0]; moderate, 5.9 [2.7]; severe, 5.7 [2.6]), for "I am very concerned about the possible side effect of my HS treatment and prefer to stop taking it for a while if possible" was 4.5 (2.7) (mild, 4.2 [2.7]; moderate, 5.0 [2.6]; severe, 7.1 [2.4]), and for "I feel that the

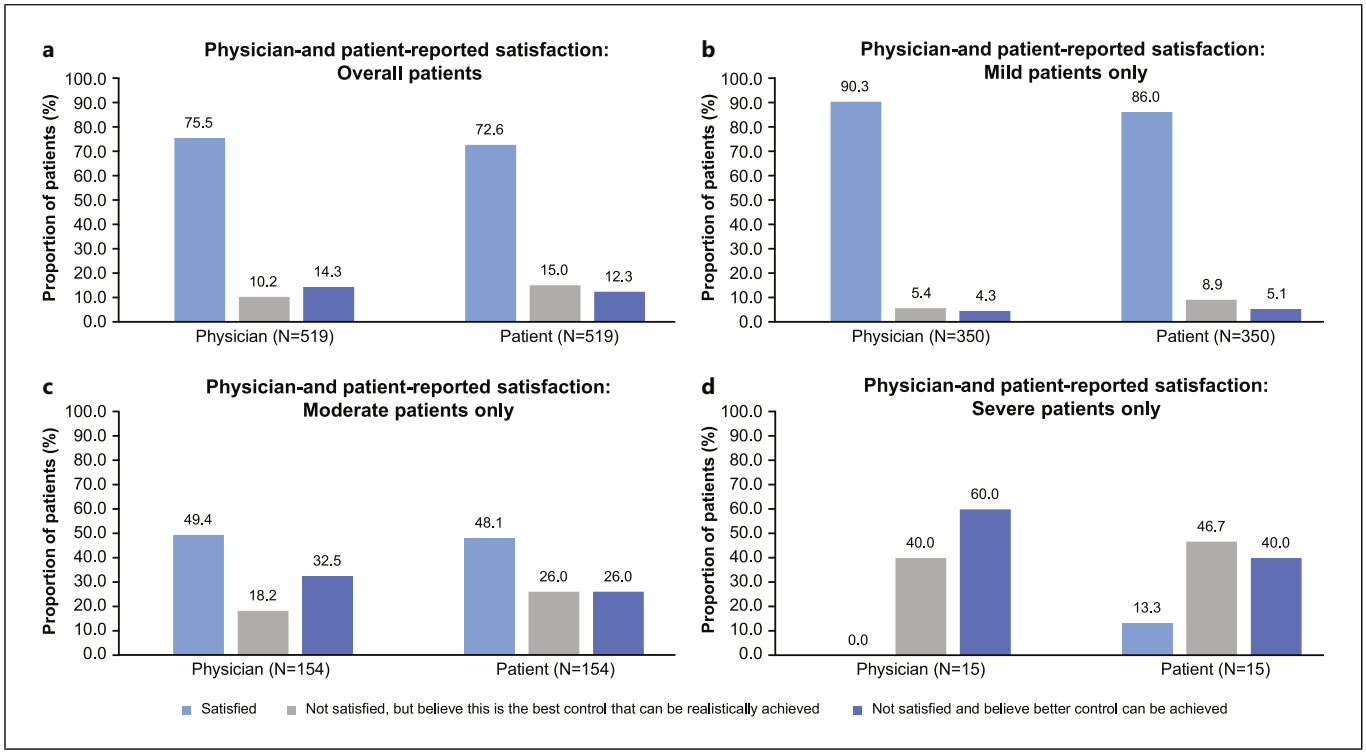

Fig. 2. Physician- and patient-reported satisfaction with current treatment control overall and based on physician-judged severity at the time of sampling. Bar graphs illustrating physician- and patient-reported satisfaction with current treatment control overall (**a**); physician- and patient-reported satisfaction with current treatment control in mild patients only (**b**); physician- and patient-reported satisfaction with current treatment control in moderate patients only (**c**); and physician- and patient-reported satisfaction with current treatment control in severe patients only (**d**). *N*, number of patients with available data.

current treatments for HS are not appropriate or very effective" was 4.0 (2.6) (mild, 3.5 [2.4]; moderate, 5.0 [2.6]; severe, 5.4 [2.4]).

Additional Results

Additional results related to order of treatment classes prescribed, treatment classes ever received, concomitant treatment, surgical treatment, and HS flares are detailed in online supplementary Tables S2, S3; Figures S2–S4 in the Supplementary Results.

Discussion

This study primarily aimed to describe the treatment patterns of patients with HS, with a particular focus on satisfaction with treatment, in a large, real-world population from the EU5 and USA, and is a follow-up to a 2022 publication describing the unmet clinical needs and burden of disease in the same patient population [33]. Due to the relative lack of large, randomized trials in HS, the evidence supporting treatment guidelines is weak [26], and real-world evidence on treatment patterns is lacking.

At HS diagnosis, regardless of disease severity, patients were most frequently prescribed topicals and oral antibiotics, which aligns with first-line treatment guideline recommendations for HS [26, 32]. At sampling, oral antibiotics and topicals remained the most prescribed treatments. Furthermore, oral antibiotics and topicals were most frequently prescribed in response to patients experiencing a flare. Long-term use of antibiotics causes known concerns, including antibiotic resistance, and has been reported to be undesirable by patients with HS [35].

Despite a large proportion of patients being diagnosed with moderate or severe disease at diagnosis, and many patients being prescribed multiple treatments concurrently, few patients were prescribed biologics (4.8%) or conventional systemics (2.5%) at diagnosis. As highlighted in previous studies, a long diagnostic delay with HS can result in disease progression and subsequently more severe disease [14, 15]. Therefore, effective treatments should be implemented

Table 2. Physician- and patient-reported reasons for dissatisfaction with current treatment control overall and based on physician-judged severity at the time of sampling

Physician-reported dissatisfaction	Overall (*N* = 127)	Physician-judged severity at the time of sampling		
		Mild (*N* = 34)	Moderate (*N* = 78)	Severe (*N* = 15)
Reason for dissatisfaction, n (%)				
Not effective enough at reducing patient's symptoms	55 (43.3)	12 (35.3)	36 (46.2)	7 (46.7)
Does not prevent flares	34 (26.8)	8 (23.5)	23 (29.5)	3 (20.0)
Other	33 (26.0)	12 (35.3)	17 (21.8)	4 (26.7)
Lack of efficacy	22 (17.3)	3 (8.8)	12 (15.4)	7 (46.7)
Not effective enough at reducing patients' pain	19 (15.0)	1 (2.9)	16 (20.5)	2 (13.3)
Efficacy diminished over time	18 (14.2)	3 (8.8)	11 (14.1)	4 (26.7)
Does not work quickly enough	17 (13.4)	2 (5.9)	11 (14.1)	4 (26.7)
Mode of administration	4 (3.1)	2 (5.9)	2 (2.6)	0 (0.0)
Severity of side effects	1 (0.8)	0 (0.0)	1 (1.3)	0 (0.0)
Number of side effects experienced	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Patient-reported dissatisfaction	**Overall (*N* = 142)**	**Physician-judged severity at the time of sampling**		
		Mild (*N* = 49)	Moderate (*N* = 80)	Severe (*N* = 13)
Reason for dissatisfaction, n (%)				
It hasn't helped the HS on certain areas of my body	43 (30.3)	14 (28.6)	27 (33.8)	2 (15.4)
I still get temporary worsening (flares)	40 (28.2)	8 (16.3)	27 (33.8)	5 (38.5)
It isn't working quickly enough	40 (28.2)	9 (18.4)	26 (32.5)	5 (38.5)
I think there are better medicines	29 (20.4)	11 (22.4)	14 (17.5)	4 (30.8)
My HS is still visible to other people	29 (20.4)	9 (18.4)	18 (22.5)	2 (15.4)
It is becoming less effective over time	28 (19.7)	8 (16.3)	19 (23.8)	1 (7.7)
I can't live a normal life	26 (18.3)	6 (12.2)	17 (21.3)	3 (23.1)
It doesn't help decrease my pain	21 (14.8)	2 (4.1)	13 (16.3)	6 (46.2)
It doesn't help decrease my itching	20 (14.1)	4 (8.2)	11 (13.8)	5 (38.5)
I don't always remember to take it when I should	17 (12.0)	9 (18.4)	7 (8.8)	1 (7.7)
Other	13 (9.2)	7 (14.3)	5 (6.3)	1 (7.7)
I would prefer to take it once every 3 months	12 (8.5)	5 (10.2)	6 (7.5)	1 (7.7)
I don't know enough about the drug	11 (7.7)	6 (12.2)	5 (6.3)	0 (0.0)
I would prefer to take it once a month	11 (7.7)	7 (14.3)	4 (5.0)	0 (0.0)
I may become dependent on it	8 (5.6)	5 (10.2)	2 (2.5)	1 (7.7)
The medicine is too expensive	8 (5.6)	3 (6.1)	3 (3.8)	2 (15.4)
I want flexible dosing (increase or decrease to address flares)	8 (5.6)	4 (8.2)	4 (5.0)	0 (0.0)
It has caused side effects/infections	7 (4.9)	3 (6.1)	3 (3.8)	1 (7.7)
It is difficult to take	4 (2.8)	3 (6.1)	1 (1.3)	0 (0.0)
It is painful when I take it	4 (2.8)	1 (2.0)	2 (2.5)	1 (7.7)
It is painful after I take it	3 (2.1)	1 (2.0)	1 (1.3)	1 (7.7)

"Other" refers to reasons other than those listed in the questionnaire. HS, hidradenitis suppurativa; *n*, number of patients with outcome; *N*, number of patients with available data.

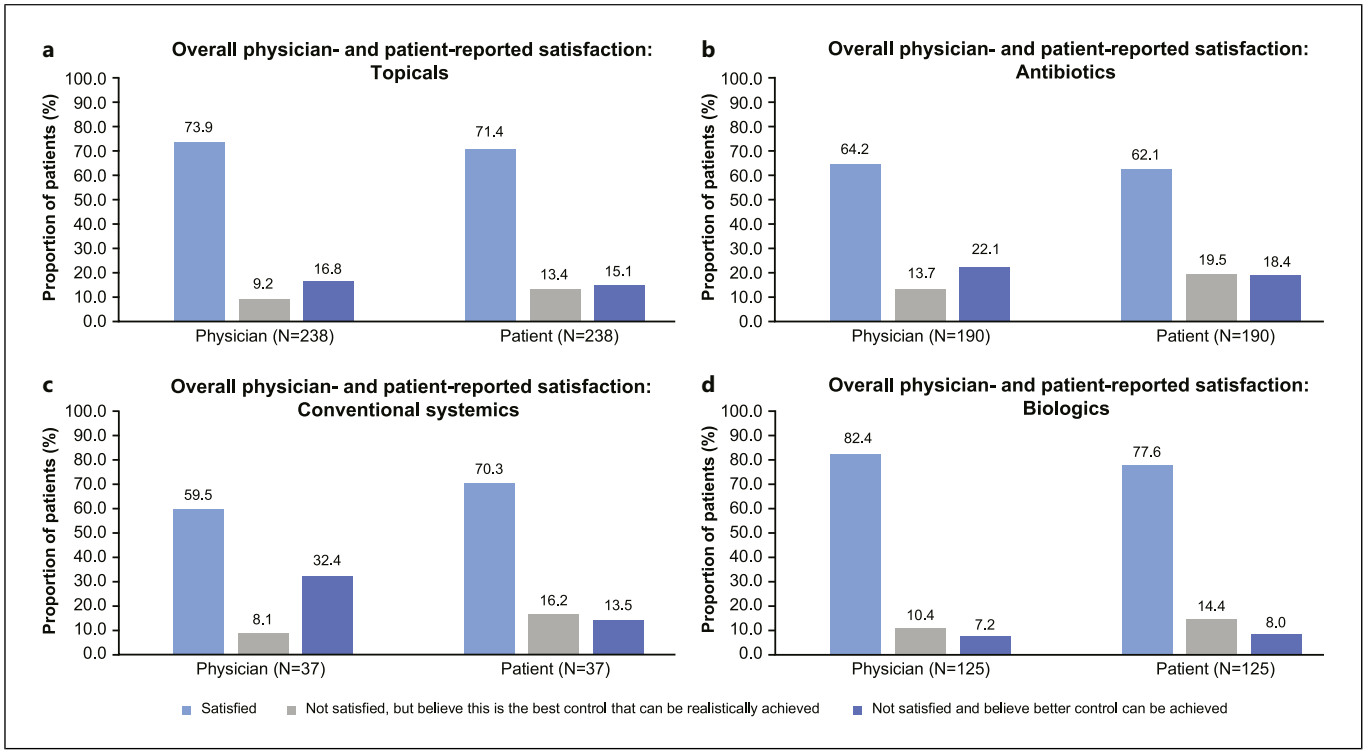

Fig. 3. Physician- and patient-reported satisfaction with current treatment control based on current treatment overall at the time of sampling. Bar graphs illustrating physician- and patient-reported satisfaction with current treatment control with topicals (**a**); physician- and patient-reported satisfaction with current treatment control with antibiotics (**b**); physician- and patient-reported satisfaction with current treatment control with conventional systemics (**c**); and physician- and patient-reported satisfaction with current treatment control with biologics (**d**). Patients could be on multiple treatment classes. *N*, number of patients with available data.

during the "window of opportunity" to lessen the disease burden experienced by patients [36]. Although 28.4% of patients had received a biologic at some point during their HS management, a large proportion of patients with moderate or severe disease had never received a biologic, highlighting that this patient cohort may be undertreated. Furthermore, over 40% of dermatologists who reported that a patient's condition warranted use of a biologic said they did not prescribe one as they wanted to "exhaust all other treatment options first." Further, dermatologists cited "very recent diagnosis" as a reason for not prescribing a biologic, indicating that biologics are generally not considered a first-line therapy in HS, in keeping with current treatment guidelines [19, 20, 37]. The attitudes toward biologic prescription warrant a paradigm shift given that they have the most mature evidence base [32], and the potential importance of early appropriate treatment in skin diseases [38].

HS treatment guidelines recommend that only patients with moderate to severe disease are eligible for biologic treatments, potentially contributing to the low use of biologics in this current study [25]. Lack of practitioner knowledge about HS, difficulty accessing HS specialists, lack of patient input in treatment plans, and treatment costs have been identified as barriers to HS patient care, leading to inadequate disease control and pain management [39–42].

An interesting finding in the current study is that, even for patients with moderate and severe disease, a proportion of dermatologists and patients indicated that they were satisfied with the control provided by treatment. Furthermore, in patients with moderate and severe disease who were not satisfied with the disease control achieved, some dermatologists and patients believed that this was the best disease control that could be achieved. This finding may indicate that dermatologists and patients acknowledge the difficulty in achieving acceptable disease control when managing HS; this concept is further exemplified by the finding that over half of patients had not raised their treatment dissatisfaction concerns with their doctor, and of those who did/would raise it, they waited/would wait an average of 3.5 months to do so. Moreover, a positive interaction with healthcare professionals may influence patients' treatment decisions, highlighting the importance of

Table 3. Physician- and patient-reported treatment goals overall and based on physician-judged severity at the time of sampling

Physician-reported treatment goals	Overall (*N* = 522)	Physician-judged severity at the time of sampling		
		Mild (*N* = 352)	Moderate (*N* = 157)	Severe (*N* = 13)
Treatment goal, n (%)				
Improves appearance of skin	298 (57.1)	196 (55.7)	91 (58.0)	11 (84.6)
Relieves pain	285 (54.6)	159 (45.2)	117 (74.5)	9 (69.2)
Works for a long time	281 (53.8)	185 (52.6)	89 (56.7)	7 (53.8)
Works quickly	256 (49.0)	157 (44.6)	94 (59.9)	5 (38.5)
Relieves itching	222 (42.5)	136 (38.6)	80 (51.0)	6 (46.2)
Is easy to take	210 (40.2)	137 (38.9)	68 (43.3)	5 (38.5)
Is safe to take	208 (39.8)	128 (36.4)	73 (46.5)	7 (53.8)
Relieves discomfort	199 (38.1)	117 (33.2)	79 (50.3)	3 (23.1)
Improves patient adherence to therapy	46 (8.8)	32 (9.1)	14 (8.9)	0 (0.0)
Relieves a particular affected area of body	41 (7.9)	24 (6.8)	16 (10.2)	1 (7.7)
Relieves a different symptom	13 (2.5)	5 (1.4)	7 (4.5)	1 (7.7)
Patient-reported treatment goals	**Overall (*N* = 522)**	**Physician-judged severity at the time of sampling**		
		Mild (*N* = 352)	Moderate (*N* = 157)	Severe (*N* = 13)
Treatment goal, n (%)				
Improves the appearance of my skin	370 (70.9)	244 (69.3)	117 (74.5)	9 (69.2)
Reduces my pain/discomfort	359 (68.8)	231 (65.6)	117 (74.5)	11 (84.6)
Get rid of the disease	359 (68.8)	243 (69.0)	107 (68.2)	9 (69.2)
Reduces number/frequency of bumps/boils	353 (67.6)	233 (66.2)	109 (69.4)	11 (84.6)
Works quickly	303 (58.0)	205 (58.2)	90 (57.3)	8 (61.5)
Reduces discharge and smell of bumps/ boils	284 (54.4)	171 (48.6)	104 (66.2)	9 (69.2)
Reduces my need to itch	274 (52.5)	185 (52.6)	83 (52.9)	6 (46.2)
Slows disease progression	260 (49.8)	163 (46.3)	87 (55.4)	10 (76.9)
Safe and tolerable long-term treatment	230 (44.1)	145 (41.2)	78 (49.7)	7 (53.8)
Prevents my HS getting worse again	229 (43.9)	141 (40.1)	82 (52.2)	6 (46.2)
Ability to perform my daily activities/live a normal life	218 (41.8)	140 (39.8)	69 (43.9)	9 (69.2)
Prevents future flares	216 (41.4)	142 (40.3)	71 (45.2)	3 (23.1)
Is easy to take	201 (38.5)	134 (38.1)	62 (39.5)	5 (38.5)
Is safe to take	169 (32.4)	107 (30.4)	58 (36.9)	4 (30.8)
Reduces need for surgery	148 (28.4)	85 (24.1)	58 (36.9)	5 (38.5)
Other	5 (1.0)	5 (1.4)	0 (0.0)	0 (0.0)

"Other" refers to reasons other than those listed in the questionnaire. HS, hidradenitis suppurativa; *n*, number of patients with outcome; *N*, number of patients with available data.

shared treatment decisions between patients and healthcare professionals [35, 43].

Previous reports have highlighted that poor efficacy, adverse events, and increasing flare frequency are factors that negatively impact treatment satisfaction in patients with HS [16, 31], while positive attributes of treatment satisfaction include effectiveness, pain reduction, and treatment with biologic medication [31, 41, 42, 44]. These findings align with the physician- and patient-reported treatment goals and patient attitudes toward treatment reported in this current study. The relatively low use of biologics in this current analysis, especially in patients with more severe disease, may explain some of the low levels of treatment satisfaction reported. This is further highlighted by the fact that most patients who were prescribed biologics were satisfied with their treatment.

In parallel with these findings, patients with more severe disease were less likely to recommend their current treatment to other patients with HS. However, even in patients who were not satisfied with their current treatment, over half of patients would still recommend the treatment to other patients with HS, reinforcing the low expectations patients with HS have regarding treatment potential for improving HS symptoms. This further speaks to involving the patient voice in HS treatment paradigms [41, 44].

Limitations

The use of survey-based data may have been biased and influenced by individual experience. The accuracy of survey-based data also depends on the quality of data collection, which may be subject to recall bias. The selection of patients and dermatologists in this survey may also be subject to selection bias. Only patients whose HS was currently being affected and physicians who commonly treat patients with HS would be most likely included. Patient's disease classification was physician-reported, potentially having a degree of subjectivity. The survey was conducted during the COVID-19 pandemic, which resulted in several consultations occurring virtually and may have biased assessments and led to treatment-independent dissatisfaction in some patients [45]. Further, this survey was cross-sectional, which means that causality in outcomes cannot be determined or inferred.

Conclusion

Consistent with the known diagnostic delay and previous findings, this large, real-world cohort study provides evidence that patients with HS are often undertreated. Patients with HS were primarily prescribed topicals or oral antibiotics to help manage their HS, with biologics and conventional systemics prescribed in relatively few patients, despite around a third of patients having moderate or severe disease. This approach may miss the optimal therapeutic window for biologic therapy [36] and under incorporate the patient perspective in shared treatment decision-making. There remains an unmet need for disease-modifying therapies in HS that can effectively manage HS and prevent disease progression.

Key Message

In addition to a high disease burden, in a large, real-world population, patients with HS may be undertreated. Integrating the patient voice into treatment decisions may lead to better outcomes and improved treatment satisfaction.

Acknowledgments

The authors thank Philip O'Gorman, PhD, and Trudy McGarry, PhD (Novartis Ireland Ltd, Dublin, Ireland), and Rosalind Bonomally, MSc (Novartis UK Ltd, London, UK) for providing medical writing support and assistance, which was funded by Novartis Pharma AG, Basel, Switzerland, in accordance with Good Publication Practice (GPP 2022) guidelines (https://www.ismpp.org/gpp-2022).

Statement of Ethics

Using a checkbox, patients provided written informed consent for use of their anonymized and aggregated data for research and publication in scientific journals. Data collection was undertaken in line with European Pharmaceutical Marketing Research Association (1) guidelines. Each survey was performed in full accordance with relevant legislation at the time of data collection, including the US Health Insurance Portability and Accountability Act 1996 (2) and Health Information Technology for Economic and Clinical Health Act legislation (3). This research also obtained ethics approval from the Western IRB, study protocol number AG8836.

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Conflict of Interest Statement

John Ingram has acted as a consultant and/or advisory board member for AbbVie, Boehringer Ingelheim, ChemoCentryx, Citryll, Insmed, Kymera Therapeutics, MoonLake, Novartis, UCB, Union Therapeutics, and Viela Bio. John Ingram also receives an editorial stipend from the *British Journal of Dermatology* and an author honorarium from UpToDate. John Ingram is co-copyright holder of HiSQOL and Investigator and Patient Global Assessment instruments for hidradenitis suppurativa. Vincenzo Bettoli has acted as a consultant, advisory board member, and investigator, and received honoraria from AbbVie, Beiersdorf, Bioderma, Biogena, Difa Cooper, Galderma, GSK, ICF, LEO Pharma, L'Oreal, Meda, Menarini Relife, Mylan, Novartis, Pharcos Biodue, and UCB, and has received research support from AbbVie. Jasmine Espy has nothing to disclose. Georgios Kokolakis has received honoraria for participation in advisory boards, in clinical trials and/or as a speaker from AbbVie Deutschland & Co. KG, Abbott, Actelion Pharmaceuticals Ltd., Basilea Pharmaceutica Ltd., Bayer AG, Biogen IDEC, Celgene GmbH, Hexal AG, Janssen-Cilag, LEO Pharma, Lilly Deutschland, MSD Sharp & Dohme, Novartis Pharma GmbH, Parexel International, Pfizer Deutschland, Sanofi-Aventis Deutschland, and UCB Pharma. Antonio Martorell has acted as a consultant, advisory board member, and investigator and received honoraria from Novartis, AbbVie, Janssen-Cilag, UCB, Lilly, LEO Pharma, L´Oreal, Sanofi, Sandoz, and Amgen. Axel Villani has acted as a consultant for AbbVie, Almirall, Janssen, LEO Pharma, Lilly, MSD, Novartis, and UCB. Craig Richardson and Torben Kasparek are employed by Novartis Pharma AG, Basel, Switzerland. Elisa Muscianisi is an employee and shareholder of Novartis Pharmaceuticals Corporation, East Hanover, USA. Hayley Wallinger, Isabel Truman, and Emily Coak are employed by Adelphi Real World, Bollington, UK. Alexa Kimball reports grants to her institution from AbbVie, Anaptys Bio, Admirx, Bristol Myers Squibb, Eli Lilly, Incyte, Janssen, Moonlake, Novartis, Pfizer, UCB Pharma, Sanofi and Sonoma Bio; consulting fees from AbbVie, Alumis, Avalo, Boehringer Ingelheim, Eli Lilly, Novartis, Moonlake, Janssen, Pfizer, Priovant, Sonoma Bio, Sanofi, Target RWE, UCB Pharma, Union Therapeutics, ZuraBio and Ventyx; and serves on the board of directors of Almirall.

Funding Sources

This study was funded by Novartis Pharma AG, Basel, Switzerland. The sponsor subscribed to Adelphi Real World to access the data. The sponsor did not influence the original survey through either contribution to the design of questionnaires or data collection.

Author Contributions

Hayley Wallinger was involved in the survey design, data collection, and data analysis. Isabel Truman and Emily Coak were involved in data analysis. John Ingram, Vincenzo Bettoli, Jasmine Espy, Georgios Kokolakis, Antonio Martorell, Axel Villani, Craig Richardson, Torben Kasparek, Elisa Muscianisi, and Alexa Kimball provided substantial contributions to the interpretation of the data. John Ingram, Vincenzo Bettoli, Jasmine Espy, Georgios Kokolakis, Antonio Martorell, Axel Villani, Craig Richardson, Torben Kasparek, Elisa Muscianisi, Hayley Wallinger, Isabel Truman, Emily Coak, and Alexa Kimball revised and reviewed the manuscript, approved the final version of the manuscript for submission, and agreed to be accountable for the accuracy of the work.

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, one of which 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 reasonable requests for access to data should be addressed directly to Hayley Wallinger at hayley.wallinger@adelphigroup.com.

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