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ORIGINAL ARTICLE

Hidradenitis suppurativa with and without draining tunnels: A real-world study characterizing differences in treatment and disease burden

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Abstract

Background: Hidradenitis suppurativa (HS) is a chronic, inflammatory, neutrophilic skin disease associated with a considerable clinical burden. In more severe disease, subepidermal draining tunnels may form.

Objectives: To characterize the clinical profile of patients with moderate–severe HS with and without draining tunnels, and the clinical and health-related quality of life (HR-QoL) burden of draining tunnels.

Methods: Data were drawn from the Adelphi HS Disease Specific Programme™, a cross-sectional survey with retrospective data collection, across the United States, France, Germany, Italy, Spain and the United Kingdom between November 2020 and April 2021. Patients were aged ≥10 years and had HS. Clinical outcomes, recorded by physicians, comprised patient demographics and HS characteristics, symptoms and treatment. HR-QoL measures included patient and physician survey questions, and validated HR-QoL instruments.

Results: Of the 580 patients with moderate–severe HS, 46% had draining tunnels. Patients with draining tunnels had more abscesses, inflammatory nodules and scarring than those without. Patients with draining tunnels were significantly ($p < 0.05$) more likely to be treated with biologics (41% vs. 27%), but often patients with tunnels who were eligible for biologics had not received them. Patients with draining tunnels experienced significantly more inflammation/redness (73% vs. 63%), drainage from lesions (62% vs. 40%) and pain on sitting (48% vs. 37%) than those without ($p < 0.05$). Draining tunnels were also significantly associated with low mood/depression (30% vs. 18%), sleep disturbance (28% vs. 19%) and fatigue (28% vs. 18%) versus no tunnels ($p < 0.05$). Physicians agreed that patients with draining tunnels experienced a negative impact of disease compared to those without. This was reflected in patient-reported surveys and HR-QoL instruments.

Conclusions: Patients with moderate–severe HS and draining tunnels experience greater clinical and HR-QoL burden than those without, emphasizing the importance of tunnels in disease impact.

INTRODUCTION

Hidradenitis suppurativa (HS) is a chronic, inflammatory, neutrophilic skin disease that affects up to 4.1% of individuals;[1,2] estimates vary according to study methodology and by ethnicity, with the highest prevalence in African Americans (1.3%) and lower reported rates in Caucasians (<1%) and Hispanics/Latinos (<0.1%).[2,3] HS is characterized by the development of painful skin lesions, inflammatory nodules and abscesses that occur on hair-bearing skin, with a predilection for skin folds in the groin and axillary, gluteal and perianal regions.[4,5] HS begins with occlusion and inflammation of hair follicles, followed by a dysregulated immune response and potential bacterial colonization; this leads to development of nodules that are often associated with sensations of stinging/burning and heat.[6,7]

In more severe disease, deep abscesses may develop and some progress to form subepidermal draining tunnels (also described as fistulae or sinus tracts) that are unique to HS, associated with chronic, malodorous discharge and are often an active source of inflammation.[7,8] The proportion of deep abscesses that develop into a draining tunnel is unknown.

HS carries a high disability and health-related quality of life (HR-QoL) burden due to pain caused by manifestations such as inflammation and scarring, as well as other physical and psychological impacts.[9,10] The prevalence of depression in patients with HS has been reported as ranging from 6% to 39%, while aspects of normal living, for example, sexual relationships, are adversely affected.[9,10] The high overall burden of HS, which is often suboptimally managed despite active treatment, has previously been described, along with the considerable impact on patients' HR-QoL.[10] However, the impact of draining tunnels on the burden of HS has not been explored in detail. This study used real-world data to explore the clinical and HR-QoL burden in patients with moderate–severe HS with and without draining tunnels.

Key points

Why was the study undertaken?

- To explore in detail the burden of draining tunnels in patients with moderate–severe hidradenitis suppurativa (HS).

What does this study add?

- Patients with draining tunnels experienced a greater disease burden compared with patients without draining tunnels.
- Physicians reported that patients with draining tunnels experienced a greater negative impact of disease overall.
- Patient-reported data indicated a greater health-related quality of life (HR-QoL) burden in patients with draining tunnels versus without.

What are the implications of this study for disease understanding and/or clinical care?

- Patients with moderate–severe HS and draining tunnels experience a greater clinical and HR-QoL burden than patients without draining tunnels.
- More effective treatments are needed for patients with draining tunnels.

METHODS

Study objectives

The aims of this study were to characterize the clinical profile of patients with moderate–severe HS with and without draining tunnels, and to explore the clinical and patient- and physician-reported HR-QoL burden of HS in these patients.

Study design

Data were drawn from the Adelphi HS Disease Specific Programme (DSP™), a cross-sectional survey with retrospective data collection. The survey ran between November 2020 and April 2021 across the United States, France, Germany, Italy, Spain and the United Kingdom. Data were collected from physician and patient surveys and patient record forms (Figure S1). The DSP methodology and generalizability have been published and validated.[11–14]

Study population

To participate, physicians had to be dermatologists involved in managing two or more patients with HS in the 12 months before data collection. All patients in this study were aged ≥10 years, had HS (assessed and confirmed by their physician) and were not enrolled in a clinical trial. No definition of HS severity was provided; severity was graded by physicians based on their knowledge of the disease. Draining tunnels were defined as linear tracts that may open onto the skin surface, with drainage expressed at rest or with compression of surrounding structures.[15]

Data collection

Physicians were screened, and those who were enrolled were asked to complete a patient record form for the next five to seven patients with HS seen at their practice who were receiving any therapy for their condition. Physicians were

only permitted to fill out a patient record form for patients who met the inclusion criteria. Patient demographics, disease characteristics, treatments and clinical burden were recorded, along with the presence or absence of draining tunnels based on the defined criteria; missing answers or responses of 'don't know' were not included in the analysis. Patients were then invited to complete a questionnaire recording their experiences of the disease and its effect on aspects of daily living. Completion of the survey by patients was voluntary and included validated HR-QoL tools.

Outcome measures

Clinical outcomes recorded comprised patient demographics, and the characteristics, symptoms and treatment (including biologic therapy) of HS. HR-QoL measures included patient and physician survey questions, and validated instruments to measure patient-reported outcomes. Physician agreement is defined as a score of 7–10 on a scale from 1 (strongly disagree) to 10 (strongly agree). Validated instruments included the well-established Dermatology Life Quality Index (DLQI; impact measured from 0 [not at all] to 30 [very much]),[16] and the newer and HS-specific 17-point Hidradenitis Suppurativa Quality of Life (HiSQOL) scale, in which impairment is graded from 0 (none) to 68 (severe).[17] Additionally, the Work Productivity and Activity Impairment questionnaire (0 [no productivity lost] to 100 [all productivity lost]) and EuroQol 5-dimensions-visual analog scale (EQ5D-VAS; 0 [worst general health] to 100 [best general health]) were employed to assess aspects of the impact on daily activities and feelings, including mood and pain.[18,19] Patients also rated their pain on a scale from 0 (no pain) to 10 (worst pain imaginable).

Statistical analysis

Patient and physician data from collection forms were linked and analysed. Comparisons between patient groups for clinical variables and HR-QoL measures were evaluated using Fisher's exact test, Student's *t*-test and Mann–Whitney *U*-test. Elastic net regression was used to determine which physician- and patient-reported variables were important predictors of HR-QoL measures and physician-reported impact of HS. All other comparisons were descriptive. Data were analysed using the Stata Statistical Software (Release 16.1, 2019; StataCorp LLC, College Station, Texas, USA). Patients with missing values for a variable were removed from analyses involving that variable.

RESULTS

Data collection

A total of 312 dermatologists (81 from the United States, 50 from the United Kingdom and 181 from the four European Union countries) completed 1787 patient record forms. Patient questionnaires were completed by 568 patients (Table S1).

Patient and disease characterization

There were 580 patients with moderate–severe HS and explicit data on the presence/absence of draining tunnels at the time of data collection: 264 (46%) with draining tunnels and 316 (54%) without (Figure S2). Over four-fifths (83%) of patients classified as having severe HS had draining tunnels. Demographic characteristics, including sex and body mass index, were similar between patients with and without draining tunnels (Table 1). Patients with draining tunnels were significantly older and had significantly more abscesses, inflammatory nodules and scarring than patients without draining tunnels ($p < 0.05$ for each; Table 1).

Clinical and HR-QoL burden of moderate–severe HS with and without draining tunnels

A significantly greater proportion of patients with draining tunnels reported experiencing inflammation/redness (73% vs. 63%), drainage from lesions (62% vs. 40%), pain on sitting (48% vs. 37%) and malodorous drainage (41% vs. 21%) than those without draining tunnels ($p < 0.05$ for each; Figure 1). Presence of draining tunnels was also significantly associated with low mood/depression (30% vs. 18%), sleep disturbance (28% vs. 19%) and fatigue (28% vs. 18%) versus no draining tunnels ($p < 0.05$ for each).

A greater proportion of physicians reported that patients with moderate–severe HS and draining tunnels experienced a great (negative) impact of disease overall (51% vs. 31%) compared with those without draining tunnels, and agreed that HS impacted their daily lives (81% vs. 65%), mental health (66% vs. 49%) and sexual function (66% vs. 50%), with greater emotional upset (77% vs. 59%; Figure 2). Significant differences ($p < 0.05$) were observed for these factors between patient groups.

Patients with draining tunnels experienced greater negative effects of their disease on aspects such as motivation, freedom to eat/drink, ability to do everyday things and financial situation, compared with patients without draining tunnels ($p < 0.05$ for each; Figure 3a). Patients with draining tunnels reported higher pain scores (mean pain score 4.80 vs. 4.05; $p < 0.05$) and a greater proportion reported the worst level of pain (score 7–10; 29% vs. 11%; $p < 0.05$), compared with patients without draining tunnels (Figure 3b).

Although DLQI scores were similar between the two groups (10.6 vs. 9.0 [indicating a moderate effect on the patient's life]), patients with moderate–severe HS and draining tunnels reported worse HS-specific HR-QoL (HiSQOL 22.3 vs. 16.2 [indicating a moderate effect on the patient's life]; $p < 0.05$), greater overall work impairment (34% vs. 26% of productivity lost; $p < 0.05$) and worse general health (EQ5D-VAS 62.9 vs. 72.0; $p < 0.05$) compared with patients without draining tunnels.

TABLE 1 Demographics and disease characteristics of patients with moderate–severe HS at data collection.

Characteristic	Patients with draining tunnels ($n=264$)	Patients without draining tunnels ($n=316$)	p value[a]
Patient demographics			
Age, mean (SD), years	38.9 (12.1)	33.3 (12.1)	<0.001
Female, *n* (%)	146 (55)	182 (58)	0.614
BMI, mean (SD), kg/m^2	28.6 (5.0)	28.4 (5.9)	0.554
Smoking status, *n* (%)[b]			0.231
Current smoker	79 (34)	99 (35)	
Ex-smoker	65 (28)	62 (22)	
Never smoked	88 (38)	123 (43)	
Age of symptom onset, mean (SD), years[c]	29.4 (13.0)	26.1 (12.1)	0.082
Time since diagnosis, mean (SD), years[d]	4.6 (6.2)	3.3 (4.6)	0.015
HS characteristics, *n* (%)			
Hurley stage II–III	255 (97)	210 (66)	<0.001
≥2 abscesses	168 (64)	112 (35)	<0.001
≥2 inflammatory nodules	187 (71)	165 (52)	<0.001
Scarring	243 (92)	225 (71)	<0.001

Note: Percentages are rounded to the nearest whole number. Patient demographics were reported by physicians using a patient record form.

Abbreviations: BMI, body mass index; HS, hidradenitis suppurativa; SD, standard deviation.

[a]*p* values for the comparison between draining tunnel and non-draining tunnel groups were calculated using Fisher's exact test, Student's *t*-test and Mann–Whitney *U*-test.

[b]Data available for 232 patients with draining tunnels and 284 patients without draining tunnels.

[c]Age of symptom onset is a patient-reported variable and is the age of the patient when they first experienced a symptom that was later attributed to HS. This is not necessarily at the same time as diagnosis. Data available for 86 patients with draining tunnels and 90 patients without draining tunnels.

[d]Time since diagnosis is the time between HS diagnosis and the time of data collection. Data available for 177 patients with draining tunnels and 231 patients without draining tunnels.

The most predictive variables of physician-reported great impact of HS (Figure 4a), and worse quality of life (QoL) assessed via DLQI (Figure 4b) and HiSQOL (Figure 4c) included scarring, malodorous drainage, inner thighs affected, abdomen affected, low mood/depression, patient-reported worst pain (score 7–10) and infection of HS lesions/abscesses.

Treatment received by patients with moderate–severe HS

The most common treatments prescribed to treat HS were systemic antibiotics, which half of all patients received regardless of the presence or absence of draining tunnels (Table 2). Patients with draining tunnels were significantly more likely to be treated with biologics (41% vs. 27%; $p<0.05$) and corticosteroids (18% vs. 8%; $p<0.05$) than those without (Table 2). A considerable proportion of patients (58% of those with draining tunnels and 30% of those without, for whom data were available) were eligible to have been treated with biologics but many were not, as physicians first wanted to exhaust other treatment options (approximately 50%). A very recent diagnosis was also a common reason for physicians not to prescribe biologics; however, this reason was less frequently reported if a patient presented with draining tunnels compared with those who did not (19% vs. 39%; $p<0.05$; Table 3). Although 49% of patients with moderate–severe HS and draining tunnels (and 31% of those without draining tunnels) had undergone surgical incision and drainage, more than 40% of those with draining tunnels (and approximately 60% of those without) had never had any surgical intervention at the time of data collection (Table 2).

DISCUSSION

In this real-world analysis, the presence of draining tunnels in patients with moderate–severe HS was associated with a greater incidence of other clinical manifestations, such as abscesses, inflammatory nodules and scarring. Additionally, these patients were more likely to be substantially impacted by other symptoms, such as inflammation, lesion drainage, pain, depression and fatigue, than those without draining tunnels.

The presence of draining tunnels in patients with HS appears to be a surrogate for more severe disease, possibly because draining tunnels are active contributors to inflammation, containing significantly elevated levels of pro-inflammatory cytokines versus those found in the epidermis.[8] Clinically, draining tunnels are associated with pain, disability and malodorous discharge,[7,10] all factors likely to contribute to a greater disease burden. Indeed, our results identify scarring and malodorous drainage as two of the highest predictors for a greater disease burden when assessed via the DLQI and physician-reported impact of HS. This identification of malodorous drainage and scarring may demonstrate that the presence or history of draining tunnels contribute to a worse burden for patients with HS. Additionally, draining tunnels was the sixth most predictive factor for a greater disease burden when assessed via the HiSQOL. The differences in factors identified is likely due to the HiSQOL being a HS-specific measure, so it may be more sensitive to HS characteristics, for example, 'draining tunnels', compared to the general dermatology measure DLQI. Also, HiSQOL and DLQI are both patient-reported whereas the impact of HS is physician-reported, which could contribute to differences in identified factors.

In addition to having a more substantial clinical burden of disease, patients in this study with moderate–severe HS and draining tunnels experienced a more severe HR-QoL

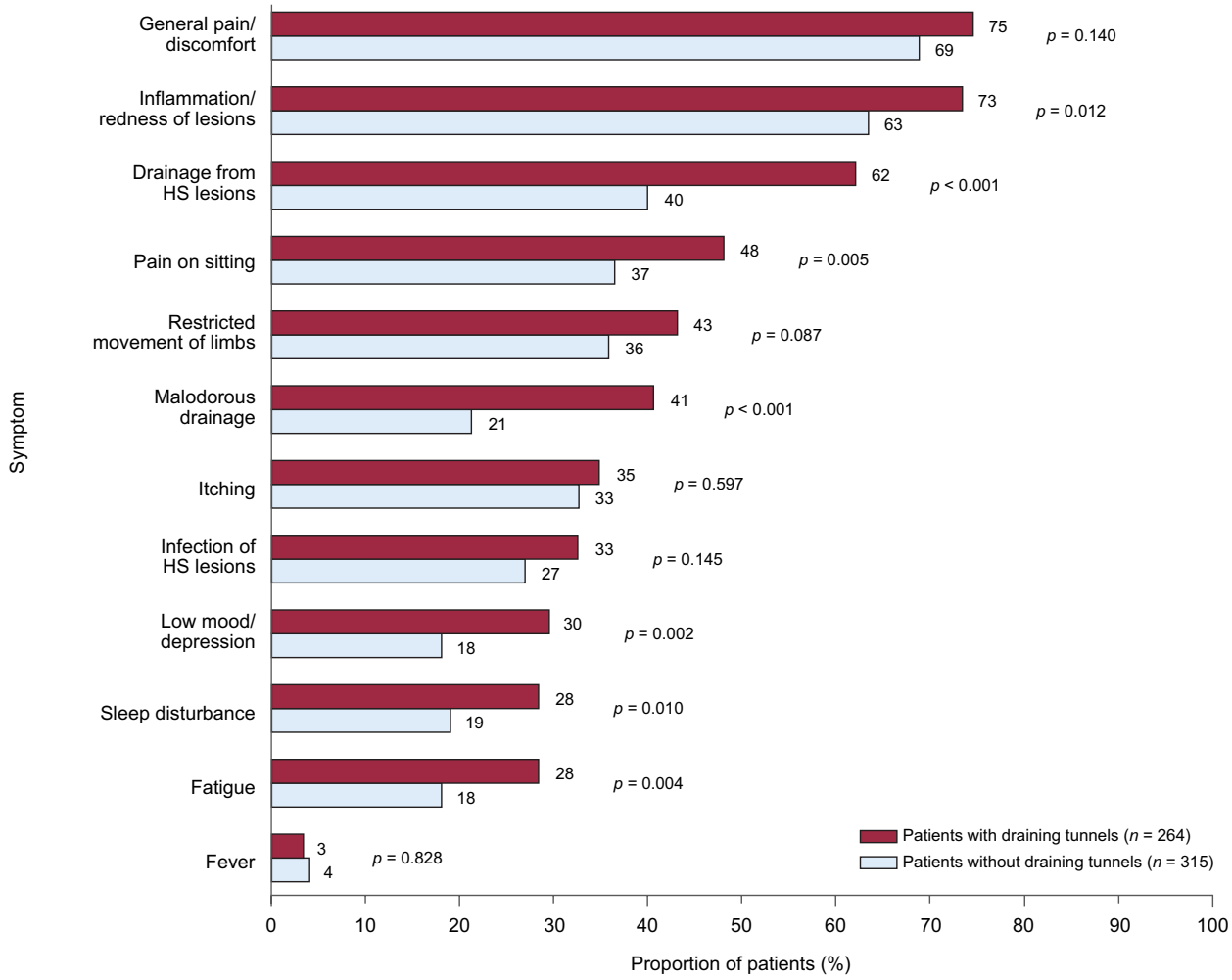

FIGURE 1 Physician-reported symptoms experienced by patients with moderate–severe HS with or without draining tunnels. HS, hidradenitis suppurativa. Symptoms were reported by physicians using a patient record form; one patient with draining tunnels and two patients without draining tunnels had no symptoms; one patient with draining tunnels and two patients without draining tunnels had other symptoms. *p* values comparing draining tunnel and non-draining tunnel groups were calculated using Fisher's exact test.

burden than patients without draining tunnels. Both dermatologists and patients reported that the presence of draining tunnels had a substantial impact on patients' everyday lives. Moreover, a greater proportion of patients with draining tunnels compared to those without reported that their condition affected their motivation, financial situation, freedom to eat/drink and ability to do everyday things. Notably, the generic DLQI instrument did not show a relevant difference in dermatology-related HR-QoL burden between patients with or without draining tunnels, whereas the HS-specific HiSQOL score indicated a greater negative impact on QoL in the draining-tunnel group. The DLQI may not capture the range of symptoms that constitute the full HS patient burden, whereas these are incorporated into the HiSQOL.[17] Work impairment and general health were also worse in patients with draining tunnels versus those without. Studies of surgical intervention and biologic therapy have shown a positive effect of these interventions on patient HR-QoL, as measured by these and other instruments.[20]

By definition, patients with HS and draining tunnels should be classified as Hurley stage II or III; this was the case for 97% of patients reported as having draining tunnels; however, 3% with draining tunnels appear to have been misclassified. This suggests that very many clinicians understand the classification system but may need more reliable methods to detect tunnelling and inform therapeutic decisions.

Patients in this study were most frequently treated with systemic antibiotics. However, a higher proportion of patients with draining tunnels received more biologic drugs and corticosteroids than those without draining tunnels. Although 58% of patients with draining tunnels (and 30% of those without) were eligible for treatment with biologic drugs, many were not receiving them at the time of data collection. When asked about this, half of all physicians said they wanted to exhaust all other treatment options first, which is at odds with the demonstrated 'window of opportunity' for biologic treatment early in the HS disease course.[21] North American and European HS management guidelines

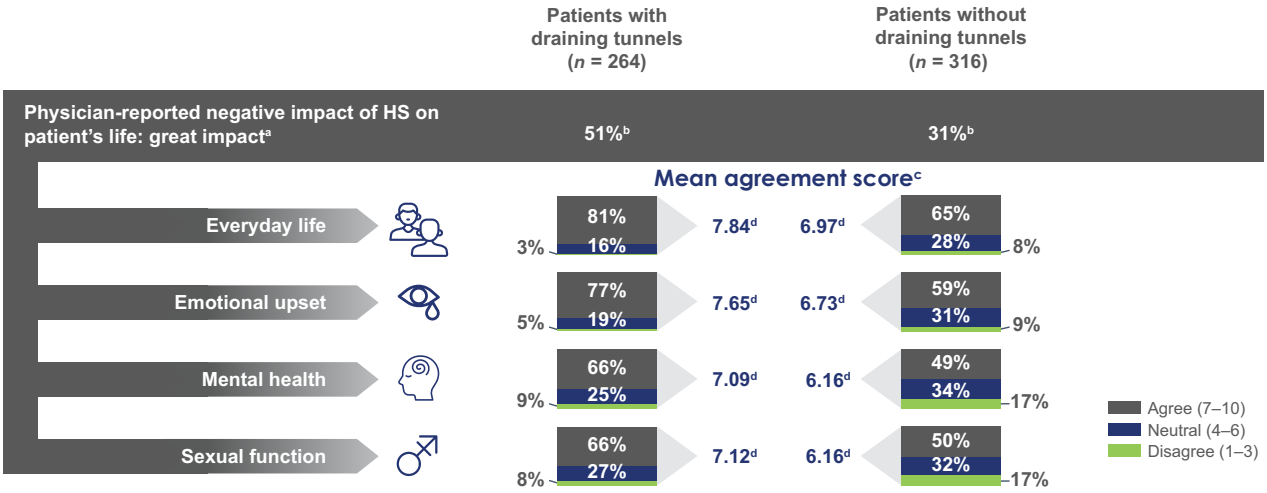

FIGURE 2 Physician-reported burden on the lives of patients with moderate–severe HS. HS, hidradenitis suppurativa. Due to rounding, percentages may not add up to 100%. [a] Scale: no impact, moderate impact, great impact. [b] $p < 0.05$ between draining tunnel and non-draining tunnel groups, calculated using Mann–Whitney *U*-test. [c] 1 = strongly disagree; 10 = strongly agree. [d] $p < 0.05$ between draining tunnel and non-draining tunnel groups, calculated using Student's *t*-test.

generally place biologic therapy at the end of the treatment pathway, which may result in missing the chance to prevent draining tunnels from increasing in number and worsening in severity after they start to form.[22] Nevertheless, existing guidelines do advocate treating the disease based both on the subjective impact on the individual patient and its objective severity.[23–25]

Until recently, the tumour necrosis factor inhibitor adalimumab was the only biologic approved in the United States and Europe for treatment of moderate–severe HS in patients aged ≥12 years,[26,27] but this and other approved HS treatments do not specifically address draining tunnels as formally described. The interleukin (IL)-17A inhibitor secukinumab has now been approved for the treatment of moderate–severe HS in adults,[28,29] based on the results of Phase 3 trials.[30] Another IL-17 inhibitor, bimekizumab, has also shown positive results in a Phase 2 trial in moderate–severe HS.[31] Given that IL-17 is expressed in draining tunnels, these drugs may offer the potential for improved outcomes in the management of HS with tunnels.[8]

The IL-36 receptor inhibitor spesolimab has been evaluated in a small, randomized proof-of-concept study in patients with moderate–severe HS.[32] In this study, there was a numerical improvement in draining tunnel count and the International Hidradenitis Suppurativa Severity Scoring System (IHS4) with spesolimab compared with placebo.[32] Therefore, the study specifically assessed efficacy regarding draining tunnels. The impact on draining tunnels may be overlooked when using the common measure of treatment efficacy, that is, the Hidradenitis Suppurativa Clinical Response (HiSCR).[33] Future clinical trials should incorporate endpoints that can measure improvements in draining tunnels.

Although surgery is recommended by guidelines,[23–25] several patients with moderate–severe HS and draining tunnels in the current study had never undergone surgical intervention. Of the patients with draining tunnels, the most common surgical intervention was incision and drainage (49%), but this is primarily used as a short-term emergency measure to relieve acute symptoms and is associated with high recurrence rates.[34] There are potential synergies between biologic drug therapy and surgery, in which the biologic is used to improve systemic inflammation before and after the procedure.[35,36] Ultimately, a combination of anti-inflammatory therapy and surgery may offer the prospect of disease resolution. However, there are drawbacks with surgical intervention, including a negative impact on patients in terms of anxiety and depression,[37] and the fact that only a select proportion of patients may be suitable to undergo surgery.[34] For example, it is challenging to offer surgery to those with multiple affected skin regions.

Strengths of the current work include that the dataset comprised a real-world cohort of patients from five European countries, plus the United States and is the first type of study to specifically focus on the impact of draining tunnels in patients with moderate–severe HS. A limitation of this analysis is that the presence of non-draining tunnels is not captured; patients with such tunnels may have been categorized as being without draining tunnels but could still have had a high disease burden. Additionally, the patients' questionnaire used in this study had pre-categorized values for abscesses, inflammatory nodules and draining tunnels; we were, therefore, unable to calculate IHS4 scores. Other limitations include disease severity being subjectively determined by the physician and a potential for sample bias towards

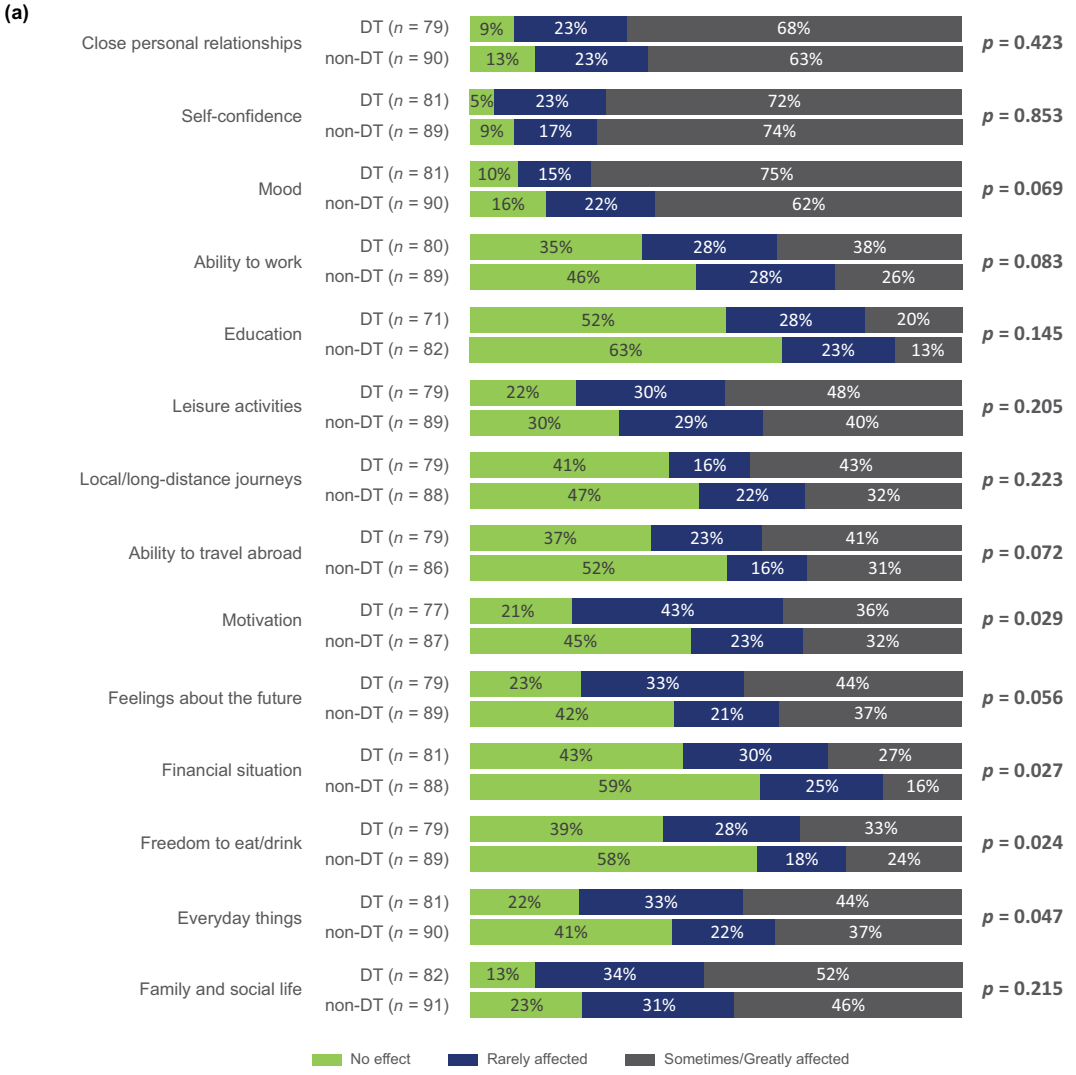

FIGURE 3 Patient-reported burden of moderate–severe HS on (a) daily life and (b) pain. DT, patients with draining tunnels; HS, hidradenitis suppurativa; non-DT, patients without draining tunnels. Due to rounding, percentages may not add up to 100%. Panel (a), *p* values comparing draining tunnel and non-draining tunnel groups, were calculated using Mann–Whitney *U*-test. Scale used in panel (a): No effect, rarely affected, sometimes affected, greatly affected. [a]0 = no pain; 10 = worst pain. [b]$p = 0.027$ between draining tunnel and non-draining tunnel group, calculated using Student's *t*-test.

patients who consult more frequently due to the consecutive nature of the sample methodology and the use of some non-HS-specific HR-QoL measures. HS-focused patient- and physician-reported outcome measures are being developed by the HIdradenitis SuppuraTiva cORe outcomes set International Collaboration (HISTORIC).[38]

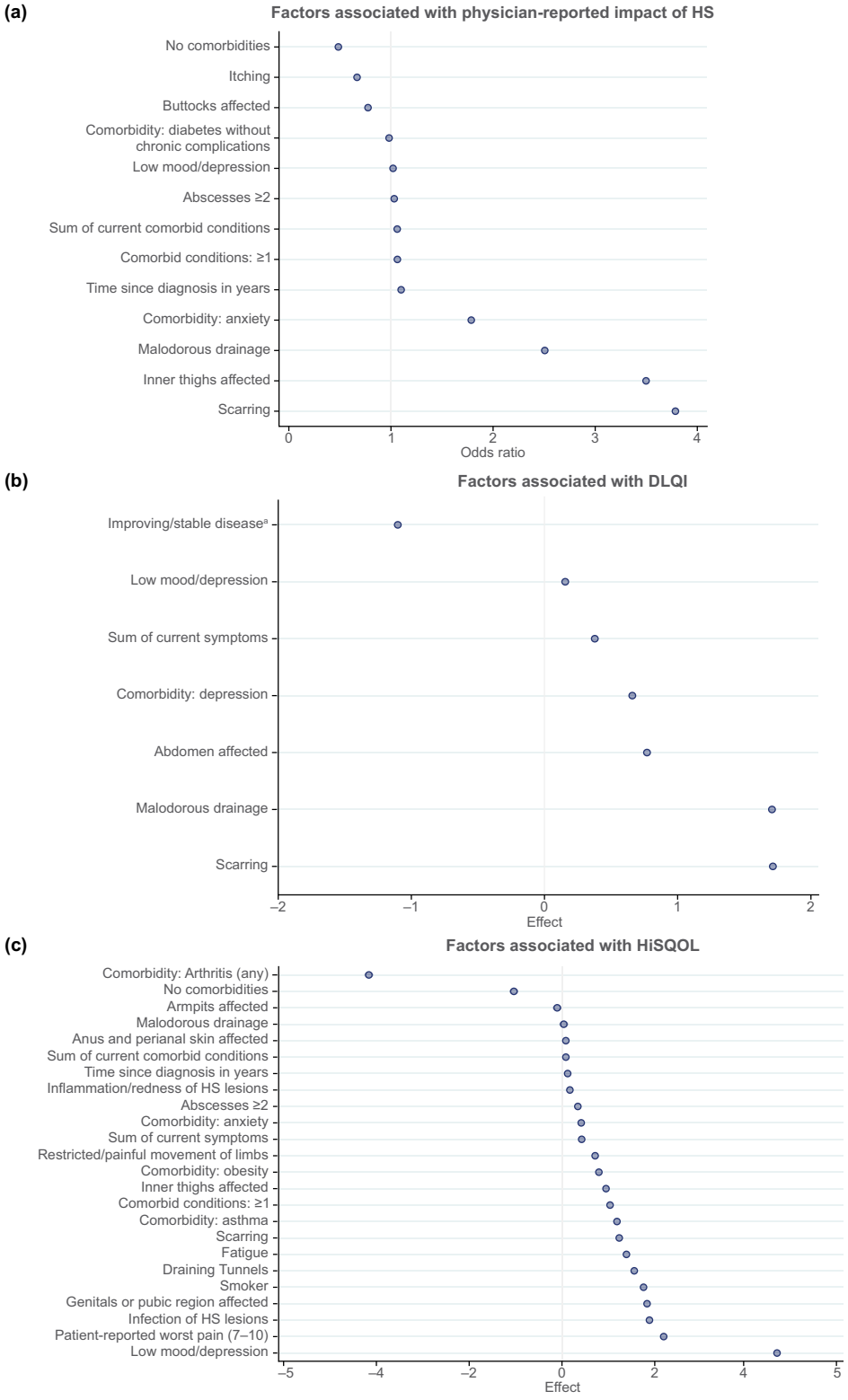

FIGURE 4 Factors most predictive of (a) physician-reported impact of HS, (b) DLQI and (c) HiSQOL. DLQI, Dermatology Life Quality Index; HiSQOL, Hidradenitis Suppurativa Quality of Life; HS, hidradenitis suppurativa. Panel (a) shows the coefficient plot from a logistical elastic net regression. The outcome of physician-reported impact was inputted into the model as 'no/moderate impact' versus 'great impact'; therefore, all factors above an odds ratio of 1 are predictive of great impact, and all factors below an odds ratio of 1 are predictive of no/moderate impact. Panels (b) and (c) show the coefficient plots from linear elastic net regression. Factors above an effect ratio of 0 are predictive of a larger patient-reported outcome score and therefore a worse impact on patient quality of life, and all factors below an effect ratio of 0 are predictive of a lower patient-reported outcome score and less impact on patient quality of life. For panels (a), (b) and (c): $n = 94$, $n = 92$ and $n = 83$, respectively. All independent variables included in the models are found in the Supplementary Appendix. [a] In the last 12 months prior to data collection.

TABLE 2 Treatment (medications and surgery) received by patients with moderate–severe HS at data collection.

Medication, *n* (%)	Patients with draining tunnels (*n* = 254)	Patients without draining tunnels (*n* = 295)	*p* value[a]
Systemic antibiotics	126 (50)	144 (49)	0.864
Biologics	103 (41)	81 (27)	0.002
Topical treatments[b]	92 (36)	122 (41)	0.221
Antiseptics	89 (35)	108 (37)	0.722
Corticosteroids[c]	45 (18)	25 (8)	0.001
Other[d]	42 (17)	52 (18)	0.820
Analgesics[e]	40 (16)	41 (14)	0.549
Conventional systemic DMARDs	20 (8)	23 (8)	1.00
Hormonal therapy	14 (6)	19 (6)	0.721
Non-biologic DMARDs	0 (0)	7 (2)	0.017
Surgery, *n* (%)	**Patients with draining tunnels (*n* = 264)**	**Patients without draining tunnels (*n* = 316)**	***p* value[a]**
None	107 (41)	192 (61)	<0.001
Surgical incision and drainage	128 (48)	99 (31)	<0.001
Local or limited excision	40 (15)	25 (8)	0.008
Wide surgical excision of all hair-bearing skin	26 (10)	24 (8)	0.374
Other[f]	20 (8)	15 (5)	0.165

Note: Data on medications were missing for 10 patients with draining tunnels and 21 patients without draining tunnels. Percentages rounded to nearest whole number. Treatments were reported by physicians using a patient record form.

Abbreviations: DMARD, disease-modifying antirheumatic drug; HS, hidradenitis suppurativa.

[a]*p* values comparing draining tunnel and non-draining tunnel groups were calculated using Fisher's exact test.

[b]Includes topical steroids, topical non-steroids and topical antibiotics.

[c]Includes oral corticosteroids and corticosteroid injections.

[d]Includes oral anti-diabetic drugs and retinoids.

[e]Includes non-steroidal anti-inflammatory drugs, cyclooxygenase-2 inhibitors, non-opioid analgesics and opioid analgesics.

[f]Other surgical interventions received by <5% of patients in each group were punch deroofing; marsupialization, exteriorization, or broader deroofing; or other unspecified surgery.

Future research characterizing the independent effect of draining tunnels on the well-being of patients with HS should objectively assess disease severity with inclusion of a draining tunnel count. Therefore, absolute numbers of HS characteristics should be recorded in future studies to allow the objective assessment of disease severity with measures such as IHS4. The use of specific and validated measures that quantify draining tunnels will help to further define the burden of disease in these patients.

TABLE 3 Treatment of moderate–severe HS with biologics at data collection.

	Patients with draining tunnels (*n* = 161)	Patients without draining tunnels (*n* = 228)	*p* value[a]
Patients in whom HS warranted biologic therapy, *n* (%)[b]	94 (58)	69 (30)	<0.001
Main reasons given by physicians for why patients were not receiving a biologic, *n* (%)			
Physician preference to exhaust other treatment options first	82 (51)	109 (48)	0.607
Very recent diagnosis	31 (19)	89 (39)	<0.001
Patient dislike of injections/infusions	22 (14)	28 (12)	0.759
Patient reluctance due to time commitments	20 (12)	17 (7)	0.115
Concerns regarding risk of infection	15 (9)	11 (5)	0.099

Note: Data available for a subset of patients only. Percentages rounded to nearest whole number. Biologic eligibility was reported by physicians using a patient record form.

Abbreviation: HS, hidradenitis suppurativa.

[a]*p* values comparing draining tunnel and non-draining tunnel groups were calculated using Fisher's exact test.

[b]As defined by the treating physician.

CONCLUSIONS

In clinical practice, patients with moderate–severe HS and draining tunnels experience a more substantial clinical and HR-QoL burden than patients without draining tunnels, highlighting an unmet need for more effective treatment approaches in this population.

AUTHOR CONTRIBUTIONS

JRI, AVM, EP, SS-B, RBW, ACHD and **ABK**: Writing—review and editing (equal). **AK**: Formal analysis (equal), visualization (equal) and writing—review and editing (equal). **RJ**: Conceptualization (lead), formal analysis (lead) and writing—review and editing (lead).

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CONFLICT OF INTEREST STATEMENT

The authors met criteria for authorship as recommended by the International Committee of Medical Journal Editors. The authors did not receive payment related to the development of this manuscript. Boehringer Ingelheim was given the opportunity to review the manuscript for medical and scientific accuracy, as well as intellectual property considerations.

JRI receives a stipend as editor-in-chief of the *British Journal of Dermatology* and an authorship honorarium from UpToDate; is a consultant for AbbVie, Boehringer Ingelheim, ChemoCentryx, Citryll, MoonLake, Novartis, UCB and UNION Therapeutics; has served on advisory boards for Insmed, Kymera Therapeutics and Viela Bio; is co-copyright holder of the Hidradenitis Suppurativa Quality of Life score, Hidradenitis Suppurativa Investigator Global Assessment and Hidradenitis Suppurativa Physician's Global Assessment instruments; and his department receives income from copyright of the Dermatology Life Quality Index and related instruments. AVM is a consultant and advisory board member for, and has received speaker fees from, AbbVie, Almirall, Boehringer Ingelheim, Eli Lilly, Janssen Cilag, Novartis, Pfizer, Sanofi Aventis, ThermoFisher and UCB. EP is a consultant and advisory board member for, and has received speaker fees from, AbbVie, Janssen, Novartis, Sandoz and UCB; and grant support (to Erasmus University Medical Center) from AbbVie, Celgene, Center for Human Drug Research, Novartis, Janssen and UCB. SS-B is a consultant and investigator for AbbVie, MoonLake Immunotherapeutics, Novartis and UCB; and is a consultant for Biogen, Boehringer Ingelheim and Hexal. RBW has received research grants from AbbVie, Almirall, Amgen, Celgene, Eli Lilly, Janssen, LEO Pharma, Novartis, Pfizer and UCB; and consulting fees from AbbVie, Almirall, Amgen, Arena, Astellas, Avillion, Biogen, Boehringer Ingelheim, Bristol Myers Squibb, Celgene, DiCE, Eli Lilly, GSK, Janssen, LEO Pharma, Novartis, Pfizer, Sanofi, Sun Pharmaceuticals, UCB and UNION Therapeutics. AK is an employee of Adelphi Real World. RJ and ACHD are employees of Boehringer Ingelheim International GmbH. ABK is a consultant for, and has received honoraria from, AbbVie, Alumis, Avalos, Boehringer Ingelheim, Eli Lilly, Evoimmune, Innovaderm, Janssen, Merck, MoonLake Immunotherapeutics, Novartis, Pfizer, Priovant, Sanofi and Sonoma Bio; has received grants for their institution from AbbVie, AnapytsBio, Aristea, Bristol Myers Squibb, Eli Lilly, Incyte, Janssen, MoonLake Immunotherapeutics, Novartis, Pfizer, Prometheus, Sanofi, Sonoma Bio and UCB; and serves on the Board of Directors for Almirall.

DATA AVAILABILITY STATEMENT

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 Aaron Keal at aaron.keal@adelphigroup.com.

ETHICAL APPROVAL

Ethical approval was granted by the Western Copernicus Group Institutional Review Board (WCG-IRB, approval number AG8836).

ETHICS STATEMENT

Patients provided written informed consent for use of their anonymized and aggregated data for research and publication in scientific journals. Data were collected in such a way that patients and physicians could not be identified directly. All data were anonymized by assigning each record a study number which could be used to pair records, and aggregated and de-identified before receipt. The survey was performed in compliance with the European Pharmaceutical Market Research Association and the US Health Insurance Portability and Accountability Act, 1996. The non-interventional, observational nature of the data collection did not result in patients being placed at risk.

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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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