Original article

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Patient experiences with hidradenitis suppurativa: the Hidradenitis Patient Experience survey

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Summary

Background. Better understanding of the experience of people living with hidradenitis suppurativa (HS) is essential to identify gaps in current patient care and inform healthcare decision-making.

Aim. To describe the patient experience of individuals with HS, including their path to diagnosis, symptom control, treatments, healthcare utilization, patient needs and impact on quality of life.

Methods. The Hidradenitis Suppurativa Patient Experience survey was created, extensively reviewed and disseminated through engaging HS-related patient organizations, physician groups and social media groups.

Results. In total, 537 respondents completed the survey; the mean age was 38 years (range 14–73 years) and 95% (510 of 537) were female. The mean number of treatment types per respondent was 15, and included antibacterial soaps (93.3%; 431 of 462), avoidance of tight clothing (90.9%; 419 of 462), use of oral antibiotics (79.7%; 368 of 462), nonprescription drugs (79.7%; 368 of 462) and topical antibiotics (77.1%; 356 of 262). Pain was poorly controlled in 46% of respondents (184 of 401). HS had a negative impact on the ability to work and attend school for 81% of respondents (337 of 415), with 59% (245 of 415) missing at least 2 days of work a month and 16% (66 of 415) missing > 11 days of work. The mean number of misdiagnoses per respondent was three and the median time to diagnosis was 10 years.

Conclusion. Individuals with HS experience a delay in diagnosis and have suboptimal control of the disease. We propose 11 recommendations to improve diagnosis, treatment and quality of life for individuals living with HS.

Introduction

Hidradenitis suppurativa (HS) is a chronic inflammatory dermatological disease characterized by recurrent painful boils and abscesses located in skin folds.[1,2] During an acute episode, the lesions develop purulent discharge and a foul-smelling odour, and may also result in scarring and fistulas.[1,2] HS affects 1%–4% of the population, is more common in women and has an average age of onset in the second decade of life.[1–3]

Previous research has demonstrated the detrimental impact of HS on the physical, psychological and social wellbeing of those affected, extending into their ability to work and to conduct activities of daily living.[4–8] However, there is a need to better understand the experiences of people living with HS to identify existing gaps in current patient care and to inform

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healthcare decision-making. This study aimed to describe the patient experience for individuals with HS and to benchmark changes in diagnosis, ongoing care and treatment for those with HS. This information provides answers to critical questions regarding gaps in patient care and deficiencies in healthcare systems.

Methods

The Hidradenitis Suppurativa Patient Experience (HSPE) survey was designed as a quality improvement initiative, and thus did not require research ethics board approval.

Development of the Hidradenitis Suppurativa Patient Experience survey

In 2017, trial investigators collaborated with a dermatologist and representatives from the Canadian Skin Patient Alliance (CSPA), Canadian Hidradenitis Suppurativa Foundation (CHSF) and HS Aware to develop an online survey titled the Hidradenitis Suppurativa Patient Experience (HSPE) survey as a quality improvement initiative for the diagnosis and treatment of HS. The survey was reviewed by trial investigators and an HS patient advocate to ensure clarity and comprehensiveness. In January 2020, the survey was updated with additional questions to more comprehensively examine the aspects of daily life that are affected. Survey items were designed to capture quantitative and qualitative aspects of the disease burden in patients with HS. Questions included information on demographics, diagnosis, healthcare journey, disease-related costs, disease impact, behaviour changes, treatments and disease knowledge (Data S1).

Survey dissemination

The survey was created on the SurveyMonkey® website (https://www.surveymonkey.com). Individuals with a formal diagnosis of HS or a self-diagnosis based on the presence of HS symptoms were invited to participate. No geographical restrictions were applied, and the survey was distributed internationally. The survey link was disseminated through the CSPA, the CHSF, and local, national and international HS patient groups. The survey was open from 6 January to 17 February 2020.

Data analysis

Data are reported as a percentage of respondents. Descriptive statistics were used to summarize survey data. Narrative analysis was used to summarize patient reported experiences of HS disease burden.

Results

Respondent demographics

In total, 537 respondents completed the survey. Mean age was 38 years (range 14–73 years) and the majority of respondents were female (95%; 510 of 537) (Table 1). Individuals were formally diagnosed with HS by a healthcare professional (HCP) in 96% of cases (515 of 537) and self-diagnosed in 4% (22 of 537). The majority of survey respondents were from the USA (50%; 267 of 537), Canada (14%; 73 of 537) and the UK (12%; 67 of 537).

Wait time and misdiagnoses

Mean wait time to be seen by a dermatologist was 84 days (Table 2), and respondents reported a mean of three misdiagnoses. The majority of individuals

Table 1 Patient demographics.

Patient demographics (n = 537)	Sample size or finding
Age, years	
Mean	38
Range	14–73
< 50, % (*n*/*N*)	85 (456/537)
> 50, % (*n*/*N*)	15 (81/537)
Sex, % (*n*/*N*)	
Female	91 (355/390)
Male	9 (36/390)
Gender, % (*n*/*N*)	
Female	91 (355/390)
Male	7 (27/390)
Genderqueer	1 (4/390)
Unspecified	1 (4/390)
Diagnosis, % (*n*/*N*)	
Healthcare provider	96 (515/537)
Self	4 (22/537)
Geographical location, *n*	
USA	267
Canada	73
UK	63
Netherlands	45
Sweden	27
Ireland	23
Australia	8
India	8
Other[a]	23

[a]Albania, Belgium, Denmark, Greece, Iceland, Malaysia, Montenegro, Morocco, New Zealand, Nigeria, North Macedonia, Puerto Rico, Singapore, Slovenia, South Africa and United Arab Emirates.

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Table 2 Healthcare journey outcomes in patients with hidradenitis suppurativa.

Outcome	Finding
Age of onset, years	29
Median wait time for dermatology consultation, days	84
Time to diagnosis, years	10
Misdiagnoses, *n*	3
Dissatisfaction with healthcare system prediagnosis, %	64
Satisfaction with healthcare system prediagnosis, %	17
Satisfaction with healthcare system postdiagnosis, %	41

were either 'dissatisfied' or 'very dissatisfied' with their healthcare system experiences while seeking a diagnosis, while the proportion of respondents who reported either 'satisfied' or 'very satisfied' was 17%.

Age of disease onset and time to diagnosis

Median time to diagnosis for respondents was 10 years and 2 months (range 1 month to 52 years), and the mean age of onset was 29 years (range 8–63 years). Respondent satisfaction with the healthcare system increased considerably after diagnosis.

Use and effectiveness of treatments

Mean number of treatment types per respondent for HS was 15 (range 1–27) (Fig. 1). The most common medical treatments included oral antibiotics (79.7%; 368 of 462), nonprescription drugs (79.7%; 368 of 462) and topical antibiotics (77.1%; 356 of 262), whereas the most common surgical intervention was incision and drainage (68.4%; 316 of 462). The most effective medical or surgical treatments were surgical treatment other than incision and drainage (39%; 62 of 159), biologics (38%; 47 of 124), radiotherapy (33%; 2 of 6) and CO_2 laser (26%; 5 of 19).

Nondrug treatments included topical antiseptics and antibacterial soaps (93.3%; 431 of 462) and avoidance of tight clothing on affected areas (0.9%; 419 of 462). Of these, the greatest improvement was seen with stress management (23%; 81 of 349) and diet modification (23%; 83 of 360), while avoidance of tight clothing was also helpful for comfort and reducing exacerbation of lesions in 18.9% of respondents (79 of 419).

Treatment goals

The primary treatment goals for respondents were to control HS symptoms (90%; 405 of 450), cure HS completely (71%; 320 of 450) and be able to enjoy personal relationships (69%; 311 of 450). The majority of respondents (61%; 275 of 450) were dissatisfied with the ability of currently available treatments and therapies to meet their treatment goals. Respondents qualitatively provided reasons for their dissatisfaction, which included the adverse effects of treatments, long wait times, an arduous recovery for surgical interventions and the high financial cost of treatments.

Pain management

Nearly all respondents experienced pain (mean daily pain score was 5.3 of 10; moderate). Pain was reported as poorly controlled by 46% (184 of 401) and reported to be very well controlled by only 11% (44 of 401). In total, 56% (225 of 401) of respondents had their pain managed by at least one HCP, primarily family physicians (20.5%; 81 of 395), dermatologists (23.8%; 94 of 395) or surgeons (4.6%; 18 of 395), whereas 44% (176 of 401) managed pain on their own.

Time spent on hidradenitis suppurativa-related activities

Respondents spent a median of 14 h and a maximum of 234 h on tasks and activities related to HS every month. The most time-consuming tasks were wound care (median 6 h; range 0–50 h) and researching HS information (median 4 h; range 0–50 h). Other reported activities included participating in patient support groups, attending medical appointments and shopping for HS-related products.

Effects on work life

HS had a negative effect on the ability to work and attend school for 81% (337 of 415) of respondents, with at least 2 days of work per month missed in 59% of cases (245 of 415) and > 11 days of work per month missed in 16% (66 of 415). Additionally, work was impacted by HS through inhibiting career progression, the impact of the disease on the individual's mental health and the necessity to adopt coping strategies (Table 3).

Effects on social life

HS had a negative effect on the ability to enjoy social interactions for 85% (354 of 415) of respondents. More specifically, social lives were impacted by HS through the inability to engage in social interactions, inability to be active, restrictions in clothing options,

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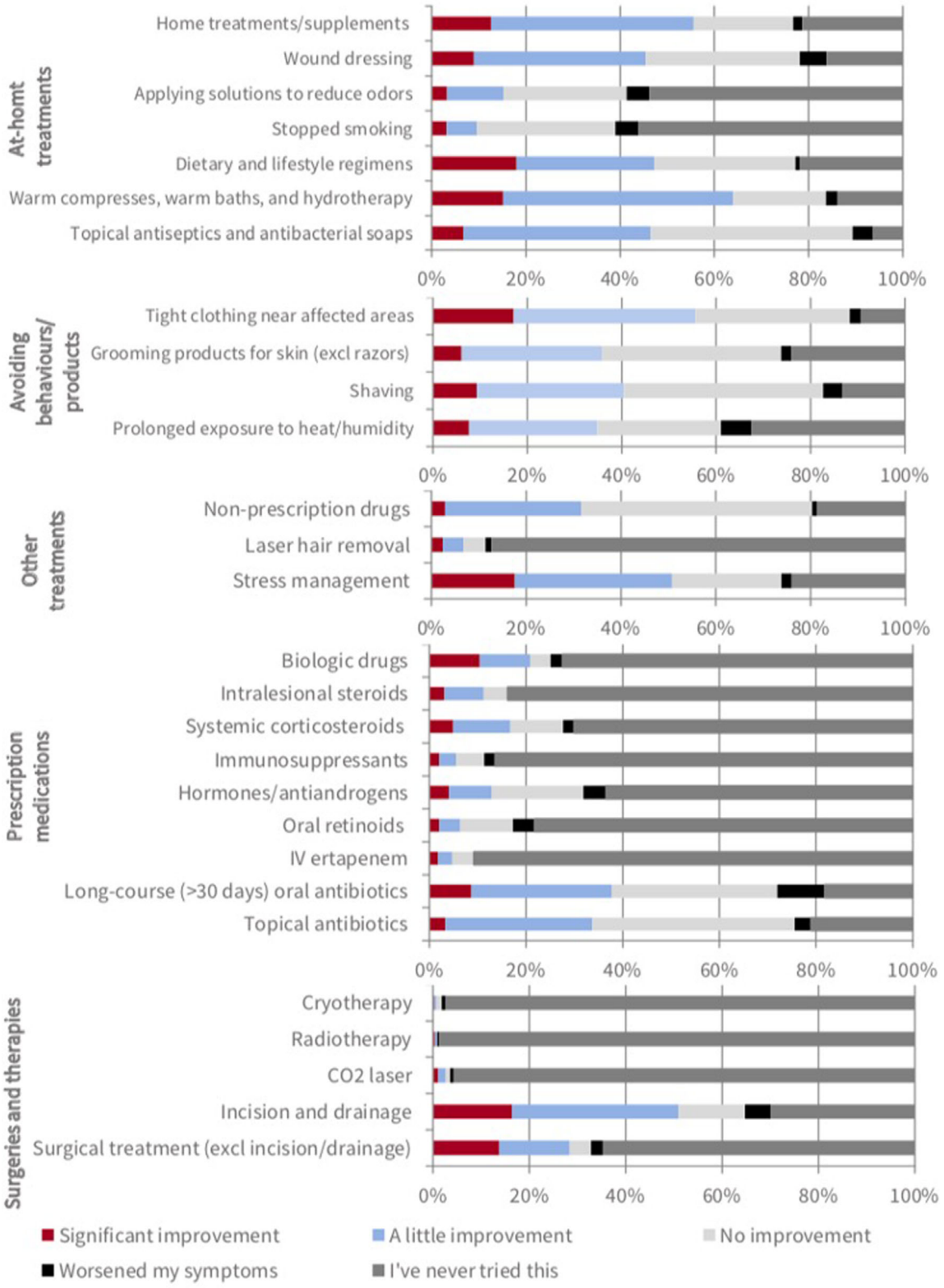

Figure 1 Effectiveness of treatments for hidradenitis suppurativa (n = 462).

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Table 3 Effects of hidradenitis suppurativa on work life, social life, family life and intimacy as reported by patients.

Effects on:	Nature of effects
Work life	Inhibits career progression
	Have to miss days or leave early due to drainage, pain and other symptoms
	Forced to go on disability benefits
	Subject to demotions, layoffs and firings due to absences
	Often unable to assume more work responsibilities because of unpredictability and debilitating symptoms
	Absences due to physical and mental symptoms, as well as complications of treatment
	Working is even more challenging prior to diagnosis as respondents do not have an official reason for absences
	Considered lazy because of inability to perform certain work tasks
	Impacts mental health
	Worry about odour, and staining of clothes and office furniture
	Stress about the possibility of a flare often triggers symptoms
	Necessity to adopt coping strategies
	Wear dark-coloured, loose clothing when possible
	Shower immediately before going to work
	Carry bandages to work and take time to re-administer dressings during shift
Social life	Inability to engage in social interactions
	Cancelling plans last minute due to symptoms is interpreted as being unreliable and leads to loss of friendship
	Cannot plan ahead for trips and other events
	Symptoms make it easy to forget about plans and events
	Work is so tiring and hard, it is often tough to force oneself to socialize after
	Sense of loss of a part of life..., i.e. can't do '_____' anymore
	Symptoms and side effects impact ability to be active
	Walking, sitting, cycling and most forms of exercise can be difficult or painful
	Cannot leave the house during a flare or a period of draining
	No water activities
	Clothing options are restricted
	Must cover up
	Cannot wear 'normal' trousers
	No tight clothing
	Impacts mental health and personal relationships
	Afraid to engage in most activities in case of pain, boil bursting, etc.
	Embarrassed by scars and questions and judgement from others
	Fearful about the weather and how it will affect odour
	So worried and stressed about leakage, that going out does not seem worth it
	Have previously heard hurtful comments and worried it will happen again
Family life	Impacts family activities
	Cannot participate in most family events
	Unable to do the activities identified as 'parenting' (attend child's events, carry or play with child, cuddle child)
	For single parents, child is housebound if parent is having a flare
	Impacts family finances
	Household income must be devoted to HS-related expenses such as medicine and clothes and to pay for personal services when respondent is in hospital for surgeries
	Impacts mental and emotional health of the whole family
	Children concerned that they will also have HS
	Feelings of sadness and a loss of hope affect the entire family
	Family feels worried about the future, particularly about the respondent getting worse or acquiring an infection
	Wound care often falls on the spouse, causing feelings of embarrassment and vulnerability for the patient
	Some respondents report hiding their condition and its impact from their family members to avoid feeling like a burden
Intimacy	Scarred by previous partner reactions
	Received pitying, judgemental or hurtful comments
	Partner assumed boils along the groin area was an STI
	Partner was concerned symptoms were contagious
	Partner was turned off by the sores that opened during sex, leading to strong odour
	Fear and anxiety about being intimate
	Self-conscious about body

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Table 3 continued

Effects on:	Nature of effects
	High levels of anxiety lead to intimacy avoidance
	Does not feel feminine
	Certain positions lead to visibility of the sores, causing embarrassment
	Fearful of beginning a new relationship and explaining HS
	Physical
	Sex causes friction, which can lead to a flare
	Inner thighs get inflamed
	Body is in too much pain to be touched
	Adverse effects of medications include lower sex drive
	Respondent no longer finds him/herself attractive because of weight gain caused by inability to exercise

HS, hidradenitis suppurativa; STI, sexually transmitted infection.

and effects on mental health and personal relationships.

Effects on family life

HS had a negative impact on family life for 68% (283 of 415) of respondents, including family activities, family finances, and the emotional and mental health of the entire family.

Effects on intimacy

HS had a negative impact on intimacy for 87% (360 of 415) of respondents through fear and anxiety about being intimate, trauma from their partner's reactions, and impedance caused by the physical symptoms of HS.

Knowledge of hidradenitis suppurativa

Information on HS and treatment options was provided to 60% of respondents by an HCP, while (216 of 360) < 20% (72 of 360) of respondents received counselling from their HCPs on the psychological impact of HS, diet and how to find support from other individuals with HS. Additionally, 45% (182 of 405) were dissatisfied or strongly dissatisfied with their HCP's understanding of HS.

Hidradenitis suppurativa-related patient needs

The HCP was regarded as a primary source of HS information by < 40% of respondents (162 of 405), and the majority of respondents turned to seeking insight and knowledge online. Additionally, 99% of respondents (403 of 407) reported they had difficulty with at least one aspect of having HS and the majority had issues with > 3 aspects (Fig. 2). Most commonly, managing symptoms, lack of disease awareness among HCPs and presence of depression were reported. The majority of respondents indicated that a truly effective treatment would drastically improve their emotional and physical wellbeing as well as provide benefits to their daily life (Table 4).

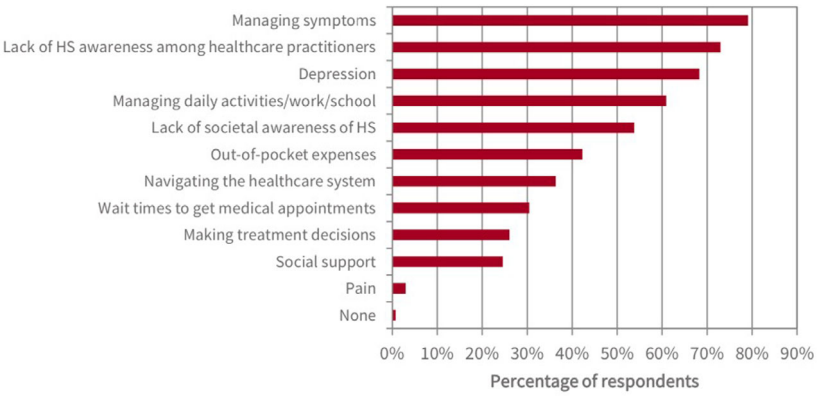

Figure 2 Areas of difficulty for individuals with hidradenitis suppurativa (n = 407).

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Table 4 Anticipated benefits of fulfilled treatment goals for hidradenitis suppurativa as reported by patients.

Emotional benefits	Physical benefits	Benefits to daily life
Less daily worry and anxiety	Be a better, more active parent to my children	More time to manage other people's problems and challenges instead of being so self-focused
Could feel normal	Be able to exercise, hike and walk more	Be less dependent on others
Not worry about shame during sex	Wear any clothing without worry	Be able to work without asking for help from others
Not have to depend on others	Not worry about pain during sex	Be able to have children
Feel attractive	Full range of motion	Have more time overall since no longer have to 'prepare' self
Happier at work and home		Be able to eat without worrying about triggering a flare

Discussion

This study summarizes results from the 2020 HSPE survey with 537 respondents. The results indicate that during their search for a diagnosis, the majority of respondents experienced long wait times for specialist consultations, received a mean of three misdiagnoses and reported dissatisfaction with the healthcare system. Median time to diagnosis was 10 years and overall mean number of treatment types was 15, while pain was poorly controlled in almost half of respondents. Further, HS had devastating impacts on work life, social life, family life and intimacy, and almost half of respondents reported dissatisfaction with their HCP's knowledge of HS.

The large number of misdiagnoses found in our survey results are in line with the relatively high prevalence of misdiagnosis found in another cohort study by Kirsten *et al.* in 2020.[9] The median time to diagnosis of 10 years found in our results is in line with several studies reporting significant delays to diagnosis,[10–12] including a retrospective review,[12] which found a median of 12 years (range 1 month to 34 years). Our results showing that the majority of respondents (61%) were dissatisfied with currently available treatments supports results from a previous survey showing that 46% of participants were dissatisfied with current treatments, and highlights the need for development of effective treatments.[13] Additionally, our results showed that the primary treatment goal for the majority (90%) of patients was to control rather than cure their HS symptoms, suggesting respondents understand that HS is a chronic disease, and stressing the impact and severity of symptoms. The high prevalence of pain in our study is in line with results from two previous surveys,[13,14] both of which showed that nearly all patients experienced pain. Additionally, our results that only 56% of respondents had their pain managed by HCPs is similar to findings from two surveys,[14,15] which found 24% and 65% of patients, respectively, received medical attention for pain. These results stress the importance of HCP inquiry into pain management and highlight the necessity for development of effective pain strategies to manage HS.[13,14] Further, our results that 59% of respondents had at least 2 days/month of HS-related work absence support previous survey results showing found that 58% of patients had HS-related absence from work, with an annual mean absence of 34 days (range 3–96 days).[16] Our finding of a negative impact on intimacy in 87% of respondents is supported by the results of a previous survey that showed a significant and unrecognized impact of HS on sexuality.[17] Further, we found negative effects on social life and family life in 85% and 68% of respondents, similar to other studies that also found significant effects in these domains.[18,19]

Based on our results, we have developed 11 recommendations (Data S2) to improve the lives of individuals with HS, which support five objectives: (i) awareness, (ii) diagnosis, (iii) treatment, (iv) care and (v) supporting patients.

This study has several limitations. First, although the sample size in 2020 was increased from that in 2017, it remains relatively small; larger sample sizes may help with the generalizability of our findings. Second, our method of recruitment may have attracted a certain population subset with HS; for example, demographic data may be reflective of a higher female presence in online support groups, which may not represent the larger population of people living with HS. Third, survey respondents may not be reflective of all patients with HS. Fourth, our results may be limited by pooling females and males into one category for data analysis, as differences between sexes in disease characteristics and treatment outcomes have been reported.[20–22] Fifth, ethnicity was not reported in our data, potentially limiting our results, as differences in race-specific prevalence of HS, access to healthcare

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resources and socioeconomic status exist.[23] Finally, recall bias may have affected the quality of our results.

Conclusion

In conclusion, results demonstrate significant psychosocial impacts of HS on people living with the disease. People with HS continue to experience delays in diagnosis and have suboptimal control of their disease. We propose 11 recommendations to improve diagnosis, treatment and quality of life for individuals living with HS.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:
Data S1. Hidradenitis Suppurativa Patient Experience (HSPE) Survey.
Data S2. Recommendations.

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