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# Access to dermatologic care and provider impact on hidradenitis suppurativa care: global survey insights

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# ABSTRACT

**Background:** Hidradenitis suppurativa (HS) is an understudied disease, and current HS studies have focused on participants already connected to dermatologic care.

**Objective:** We surveyed participants in online HS support communities to gain a comprehensive understanding of how provider type impacts HS disease management and the issues individuals with HS face when accessing care.

**Methods:** From June 13 to June 30, 2021, we administered an anonymous cross-sectional online survey to HS Facebook support group participants who had a self-confirmed diagnosis of HS. Survey items assessed respondent demographics, primary HS provider, and barriers to HS care and pain management. Descriptive analyses are presented.

**Results:** The survey was viewed 5,168 times and 1,040 surveys met eligibility criteria (20.1%). Survey participants were 97% female and 72% White. Seventy-two percentage resided in the United States and 22% in Europe. Forty-seven percentage reported having a dermatologist as their primary HS provider, 38% reported a nondermatologist, and 15% reported no HS provider. We found that Asian race, full-time employment, private health insurance, and urban setting were each associated with higher rates of having a dermatologist as a primary HS provider. However, 43.7% of those with a dermatologist reported biologic use, as compared with 14.5% with nondermatologist HS providers. Our cohort was notably more severely impacted by comorbid diseases; 55.9% of our cohort had anxiety, 53.6% had depression, and 50.7% had obesity. Overall, 74.2% of our cohort reported experiencing stigma while accessing care for their HS.

Limitations: Participant recruitment via social media platform facilitates recruitment of individuals across the spectrum of healthcare access, but may introduce selection bias and favor well-resourced areas. Self-reported data may be subject to recall bias.

**Conclusion:** Our study provides unique insights into the characteristics and experiences of individuals with HS across the spectrum of health care access.

Keywords: epidemiology, gender differences, hidradenitis suppurativa, public health, sex differences

# Introduction

Hidradenitis suppurativa (HS) is a debilitating and understudied inflammatory skin disease that negatively impacts quality of life.<sup>1-3</sup> HS patients experience a 7- to 10-year median diagnostic delay, a lack of uniformly effective treatments, and difficulty accessing dermatologic care.<sup>4-7</sup> Studies exploring the barriers to care that HS patients face are limited. The largest global HS survey study completed to date identified access to dermatology and treatment effectiveness as barriers to HS care<sup>1</sup>; however, all study participants were already connected to dermatologic care and there was limited exploration into the causes and effects of barriers experienced.

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While dermatologists primarily treat patients with HS, many patients with HS may not have access to a dermatologist. In this context, more than 60,000 patients have turned to online communities to seek support for and information about HS.<sup>8</sup>

In this study, we surveyed participants in online HS support communities to gain a comprehensive understanding of how provider type impacts HS disease management and the barriers individuals with HS face when accessing care.

What is known about this subject in regard to women and their families?

- HS is a chronic disease that disproportionately affects women.
- Previous studies have identified barriers to care, disease characteristics, and management among HS patients who have access to a dermatology.
- Other studies have assessed sources of internalized stigma among HS patients.

What is new from this article as messages for women and their families?

- Ninety-seven percent of our survey participants identified as women.
- The results of our study provide novel data on people with HS who do not see a dermatologist for their HS.

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## Methods

In this voluntary, anonymous, cross-sectional study, international participants recruited from 5 HS online support groups completed an anonymous survey from June 13 to June 30, 2021. Online support groups were identified using the keyword "hidradenitis suppurativa" in Facebook's inbuilt search engine. Individuals in groups with greater than 3,000 members or with membership comprising historically marginalized populations, including Black and Latinx individuals, were invited to participate.

The objective of this study was to assess barriers faced in accessing HS care among a large, diverse population of individuals with HS who may not have access to a dermatologist and to better understand how provider type might affect their care or disease course.

Eligible participants reported being 18 years or older, self-identified as having HS, and completed greater than 10% of the survey. Participants either reported an HS diagnosis by a medical provider or indicated they had HS based on validated screening questions.<sup>9</sup> The survey consisted of 35 items ascertaining participant demographics, HS disease characteristics, treatments received, sources of stigma experienced, barriers to HS care experienced, and primary HS provider type.

Administrators of participating online support groups were asked to post the survey link 3 times over the 17-day survey period in their respective online support groups. At the end of the survey period, group administrators provided post reach metrics, a Facebook metric that estimates the number of individuals who saw the post at least once. Post reach data were used to estimate response rate.

Descriptive statistics were used to characterize the study population. Data were stratified by provider type and disease severity to evaluate differences by these parameters.

This study was exempt from institutional review board approval by the University of California, San Francisco Institutional Review Board (Protocol #19-27407). The survey was administered in English and data were collected and stored using Qualtrics (Provo, UT).

#### Results

We received total of 1,040 responses from 42 countries. The survey had an estimated post reach of 5,168 views, yielding an estimated response rate of 20.1%. After excluding surveys with <10% completion and those completed by participants self-reporting age <18 years, 1,022 responses were deemed eligible.

The cohort was 97% (n = 963/996) female, racially diverse, and included participants from 5 continents (Table 1). The majority of respondents self-reported Hurley stage 2 (57%, n = 501/874) to Hurley stage 3 (36%, n = 315/874) HS. However, 8.1% (n = 75/927) reported being disabled due to their HS.

Notably, 46.9% ( $\hat{n} = 445/949$ ) reported having a dermatologist as their primary HS provider, while 37.9% (n = 360/949) and 15.2% (n = 144/949) reported a nondermatologist and no primary HS provider as their primary HS provider, respectively. Notably, 51.6% of participants with Hurley stages 2 and 3 HS (421/816) reported not having a dermatologist HS provider. Asian participants reported having a dermatologist as their primary HS provider (52.4%, n = 22/42) more frequently compared to other races. American Indian/Native participants more frequently reported having no HS provider (25.7%, n = 9/35) and less frequently reported dermatologist as their primary HS provider (22.9%, n = 8/35) than other races.

Participants with a high school diploma reported having a dermatologist HS provider (38.5%, n = 184/478) less frequently compared with those with higher educational attainment (college completion: 51.5%, associate degree: 52.2%, graduate degree: 48.6%). Participants with private insurance reported having a

dermatologist (51.2%, n = 234/457) more frequently compared with those with other insurance types; however, 36.2% (n = 55/152) of those without any health insurance reported having a dermatologist provider. Three of 9 individuals with Indian Health Service insurance reported having a dermatologist.

Participants residing in Europe reported having a dermatologist (35.26%, n = 73/205) and no provider (10.7%, n = 22/205) less frequently compared with those residing in other countries. Overall, those residing in urban settings (51.3%, n = 158/308) reported having a dermatologist more frequently compared with those residing in rural (40.6%, n = 110/271) and suburban settings (46.4%, n = 170/366).

Interestingly, the median diagnostic delay was shorter for those without an HS provider compared with those with a dermatologist (median [interquartile range]; overall: 12 years [3–15]; no HS provider: 9 years [3–12.75]; dermatologist: 11.5 years [3–15]; nondermatologist HS provider: 13 years [3–16]).

Notably, 59.8% of participants reported at least 3 or more comorbid conditions (Table 2). The most common comorbidities reported in our cohort were anxiety (55.9%, n = 518/927), depression (53.6%, n = 497/927), and obesity (50.7%, n = 470/927). Depression was high across all severity groups (Hurley stage 1: 50.0%, n = 29/58; Hurley stage 2: 51.8%, n = 259/500; Hurley stage 3 patients: 59.4%, n = 187/315). Suicidal ideation (SI) was reported in 13.9% (n = 129/927) of all participants with increased frequencies observed with more severe disease (I: 10.3%, n = 6/58; II: 13.8%, n = 69/500; III: 15.6%, n = 49/315). However, 16.2% (n = 51/315) of participants self-reporting Hurley stage 3 reported being disabled due to their HS.

The most frequently reported treatments among survey respondents were oral antibiotics (84.6%, n = 784/927) and cleansers/antiseptics (71.6%, n = 664/927) (Fig. 1). Those with a dermatologist more frequently used oral antibiotics (92.9%, n = 408/439) and cleansers/antiseptics (82.5%) to treat their HS, when compared with nondermatologist providers (antibiotics: 86.9%, n = 306/352; cleansers/antiseptics: 69.9%, n =246/352). However, 26.9% (n = 249/927) of all participants reported using biologics to treat their HS. Notably, 43.7% (n = 192/439) of those with a dermatologist reported biologic use, as compared with 14.5% (n = 51/352) with nondermatologist HS provider. Among those with Hurley stage 2 or 3 disease, 46.6% (n = 184/395) of those with a dermatologist were prescribed biologics, compared with 16.4% (n = 50/305) of those with a nondermatologist provider. Those with nondermatologist HS providers were more likely to report hormonal treatments (86.9%, n = 306/352) compared with dermatologists (48.3%, n = 306/352)n = 212/439). Thirty-seven percentage (n = 343/927) of all participants reported using dietary modifications to treat HS. This was most frequent among those with a dermatologist (41.5%, n)= 182/439). Thirty-two patients used no treatments at all. This was more common among those with no HS provider (no provider: 23.5%, *n* = 32/136; dermatologist: 0.5%, *n* = 2/439; nondermatologist HS provider: 1%, n = 3/352).

The most frequently reported barriers to care in our cohort were lack of treatment options (54.1%, n = 504/931), limited provider knowledge about HS (50.3%, n = 463/931), and availability for appointments (36.0%, n = 335/931) (Fig. 2). Lack of treatment options (nondermatologist: 60.1%, n = 212/353; dermatologist: 46.4%, n = 64/138) and provider knowledge (nondermatologist: 58.1%, *n* = 205/353; dermatologist: 48.6%, n = 67/138) were frequently reported among both those with nondermatologist HS providers and dermatologists. Availability of appointments was a barrier more frequently reported among those with a dermatologist (dermatologist: 41.1%, n = 181/440; nondermatologist: 34.3%, n = 121/353). About 20.3% (n = 189/931) of all participants reported provider bedside manner as a barrier to HS treatment, and rates were similar regardless of HS provider type (dermatologist: 20.0%, n = 88/440; nondermatologist: 21.5%, n = 76/353; no provider: 18.1%, n = 25/138). Distance to provider (dermatologist: 21.4%,

#### Table 1

#### Demographics of participant cohort by HS provider type

$ \begin{array}{ c c c c c c c c c c c c c c c c c c c$		Dermatologist provider		Nondermatologist provider		No provider		All	
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Set $\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$	Total	445	46.9%	360	37.9%	144	15.2%	949	100%
Fenale     431     44.8%     385     41.0%     137     14.2%     963     97%       White     342     44.6%     320     41.7%     105     13.7%     767     77.0%       Black     46     44.2%     40     38.5%     18     17.3%     104     10.4%       HispaniClatinx     33     45.6%     28     39.9%     11     15.3%     72     72%       Asian     22     52.4%     12     28.6%     9     25.7%     35     3.5%       Anter-BreakmanPacific Islander     0     0.0%     0     0.0%     2     0.2%       Other Authon Poweling Pacific Islander     0     0.0%     2     40.0%     2     0.2%       Other Authon Poweling Pacific Islander     0     0.0%     2     46.0%     3.1%     11     17.5%     463     48.9%       Call poweling Completion     106     51.5%     78     37.0%     22     10.7%     206     24%       Graduate education     51	Sex								
Racademinicing within the second seco	Female	431	44.8%	395	41.0%	137	14.2%	963	97%
White     342     44.6%     320     41.7%     105     13.7%     767     77.0%       Black     44.6%     40.38.5%     18     17.3%     104     10.4%       Hispanic/Laira     33     45.8%     28     38.9%     11     15.3%     72     72.9%       Araner fcan Indian/Alaskan Native     8     22.9%     18     61.4%     9     25.7%     35     35.5%       Anarer fcan Indian/Alaskan Native     8     22.9%     18     61.4%     9     25.7%     35     35.5%       Schooling     23     45.1%     22     43.1%     6     11.8%     51     5.1%       Schooling     22     17.7%     122.4%     47.7%     12.6%     48     48%       Callage completion     106     51.5%     76     37.9%     22     10.7%     206     224     12.8%     101     14%       Graduate education     51     46.6%     40     38.1%     14     13.3%     105     51%	Race/ethnicity								
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Hispanic/Lativa     33     45.8%     28     38.9%     11     15.3%     72     72.8       Anane can Indian/Maskan Native     8     22.9%     18     51.4%     9     25.7%     35     3.5%       Other/unknown/daclinel     23     45.1%     22     43.1%     6     11.8%     51     51%       Schooling     Elementary education     31     49.2%     21     33.3%     11     17.5%     63     6%       High school diploma     184     32.8%     220     46.0%     74     15.5%     47.8     47.3     47.8     47.8     47.8     47.8     47.8	Black	46	44.2%	40	38.5%	18	17.3%	104	10.4%
$ \begin{array}{c c c c c c c c c c c c c c c c c c c $	Hispanic/Latinx	33	45.8%	28	38.9%	11	15.3%	72	7.2%
$\begin{array}{c c c c c c c c c c c c c c c c c c c $	Asian	22	52.4%	12	28.6%	7	16.7%	42	4.2%
Native Hawaiian/Pacific Islander     0     0.0%     2     100.0%     2     0.0.0%     2     0.0.0%     2     0.0.0%     2     0.0.0%     2     0.0.0%     2     0.0.0%     2     0.0.0%     2     0.0.0%     5     0.0.0%     5     0.0.0%     5     0.0.0%     5     0.0.0%     5     0.0.0%     5     0.0.0%     5     0.0.0%     5     0.0.0%     0     0.0.0%     7     1     5.5%     6.3     6%     0.00%     0     0.0.7%     2.06     21%     3.6     14%     3.6     0.6     2.1     0.3.3%     11     1.5.%     4.7%     4.4%     6.0     1.1%     1.1%     1.05     1.1%     1.05     1.1%     1.05     1.1%     1.05     1.1%     1.05     1.1%     1.05     1.1%     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05     1.05 <td>American Indian/Alaskan Native</td> <td>8</td> <td>22.9%</td> <td>18</td> <td>51.4%</td> <td>9</td> <td>25.7%</td> <td>35</td> <td>3.5%</td>	American Indian/Alaskan Native	8	22.9%	18	51.4%	9	25.7%	35	3.5%
Other Luknown/declined     23     45.1%     22     43.1%     6     11.8%     51     5.1%       Schooling     31     49.2%     21     33.3%     11     17.5%     63     6%       High school diploma     184     38.5%     220     46.0%     74     15.5%     473     478     478     48%       College completion     106     51.5%     78     37.9%     22     10.7%     206     21%       Associates degree     71     52.2%     43     31.6%     14     13.3%     105     114%       Employed full time     239     47.7%     190     37.9%     72     14.4%     50     55%     91     10%       Bendeyde full time     239     45.5%     52     47.3%     19     17.3%     110     12%       Baled     42     43.5%     36     52.9%     8     11.8%     68     7%       Other     24     44.4%     33.3%     12     22.5%     54 <t< td=""><td>Native Hawaiian/Pacific Islander</td><td>0</td><td>0.0%</td><td>0</td><td>0.0%</td><td>2</td><td>100.0%</td><td>2</td><td>0.2%</td></t<>	Native Hawaiian/Pacific Islander	0	0.0%	0	0.0%	2	100.0%	2	0.2%
Schooling     Schooling       Elementary education     31     49.2%     21     33.3%     11     17.5%     63     6%       High school diploma     184     38.5%     220     46.0%     74     15.5%     47.8     49%       College completion     106     51.5%     78     37.9%     22     16.2%     13.6     14%       Graduate education     51     48.6%     40     38.1%     14     13.3%     105     11%       Employed rul time     239     47.7%     190     37.9%     72     14.4%     501     53%       Employed rul time     46     42.2%     47.3%     19     17.3%     110     12%       Bonemaker     39     35.5%     52     47.3%     12     22.2%     54     6%       Other     24     44.4%     18     33.3%     12     22.2%     54     6%       Bustoled     10     58.6%     60     38.5%     77     79.9%     39     4%	Other/unknown/declined	23	45.1%	22	43.1%	6	11.8%	51	5.1%
Elementary education     31     49.2%     21     33.3%     11     17.5%     63     6%       High school diploma     184     38.5%     220     40.%     74     15.5%     478     49%       College completion     106     51.5%     78     37.9%     22     10.7%     206     21%       Associates degree     71     52.2%     43     31.6%     124     13.3%     105     11%       Employed full time     239     47.7%     190     37.9%     72     14.4%     501     53%       Employed full time     46     42.2%     46     42.2%     19     17.3%     110     12%       Homemaker     39     35.5%     52     47.3%     19     17.3%     110     12%       Desabled     45     49.5%     41     45.1%     5     5.5%     91     10%       Interner     24     44.4%     18     33.3%     12     22.5%     54     6%     65     12.0%	Schooling								
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$\begin{array}{cccl} College completion & 106 & 51.5\% & 78 & 37.9\% & 22 & 10.7\% & 206 & 21\% \\ Associates degree & 71 & 52.2\% & 43 & 31.6\% & 22 & 16.2\% & 136 & 14\% \\ Stociates degree & 71 & 52.2\% & 43 & 31.6\% & 22 & 16.2\% & 136 & 14\% \\ Catulate education & 51 & 48.6\% & 40 & 38.1\% & 14 & 13.3\% & 105 & 11\% \\ Employed full time & 239 & 47.7\% & 190 & 37.9\% & 72 & 14.4\% & 501 & 53\% \\ Employed full time & 46 & 42.2\% & 46 & 42.2\% & 17 & 15.6\% & 109 & 12\% \\ Homemaker & 39 & 35.5\% & 52 & 47.3\% & 19 & 17.3\% & 110 & 12\% \\ Disabled & 45 & 49.5\% & 41 & 45.1\% & 5 & 5.5\% & 91 & 10\% \\ Unemployed & 24 & 35.3\% & 36 & 52.9\% & 8 & 11.8\% & 68 & 7\% \\ Other & 24 & 44.4\% & 18 & 33.3\% & 12 & 22.2\% & 54 & 6\% \\ Student & 18 & 46.2\% & 14 & 35.9\% & 7 & 17.9\% & 39 & 4\% \\ Retired & 10 & 58.8\% & 4 & 23.5\% & 3 & 17.6\% & 17 & 2\% \\ Insurance & & & & & & & & & & & & & & & & & & &$	High school diploma	184	38.5%	220	46.0%	74	15.5%	478	48%
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Graduate education     51     48.6%     40     38.1%     14     13.3%     105     11%       Employed full time     239     47.7%     190     37.9%     72     14.4%     501     53%       Employed full time     46     42.2%     46     42.2%     17     15.6%     109     12%       Disabled     45     49.5%     41     45.1%     5     5.5%     91     10%       Unemployed     24     35.3%     36     52.9%     8     11.8%     68     7%       Other     24     44.4%     18     33.3%     12     22.2%     54     66       Student     18     46.2%     14     35.9%     7     17.9%     39     4%       Retired     10     58.8%     14     23.5%     3     17.6%     17     20%       Insurance     79     50.6%     60     38.6%     12     15%     19     2%       Other     13     41.9%	Associates degree	71	52.2%	43	31.6%	22	16.2%	136	14%
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Émployed fult lime     239     47.7%     190     37.9%     72     14.4%     501     53%       Employed part time     46     42.2%     16     42.2%     17     15.6%     109     12%       Homemaker     39     35.5%     52     47.3%     19     17.3%     110     12%       Disabled     45     49.5%     41     45.1%     5     5.5%     91     10%       Unemployed     24     44.4%     18     33.3%     12     22.2%     54     6%       Student     18     46.2%     14     35.9%     7     17.9%     39     4%       Retired     10     58.8%     4     23.5%     3     17.6%     17     2%       Insurance     79     50.6%     60     38.5%     17     10.9%     156     168       No health insurance     79     50.6%     56     36.8%     41     27.0%     152     15%       Other     13     41.9%	Employment								
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	Employed full time	239	47.7%	190	37.9%	72	14.4%	501	53%
Homemaker     39     35.5%     52     47.3%     19     17.3%     110     12%       Disabled     45     49.5%     41     45.1%     5     5.5%     91     10%       Unemployed     24     35.3%     36     52.9%     8     11.8%     68     7%       Other     24     44.4%     18     33.3%     12     22.2%     54     6%       Student     18     46.2%     14     35.9%     7     17.9%     39     4%       Retired     10     58.8%     4     23.5%     3     17.6%     17     2%       Insurance     79     50.6%     60     38.5%     17     10.9%     156     16%       Nothealth insurance     79     50.6%     66     36.8%     41     27.0%     152     15%       Indian Health Service     3     3.3.3%     4     44.4%     2     22.2%     9     1%       Indian Health Service     3     3.3.3%	Employed part time	46	42.2%	46	42.2%	17	15.6%	109	12%
$\begin{array}{c c c c c c c c c c c c c c c c c c c $	Homemaker	39	35.5%	52	47.3%	19	17.3%	110	12%
Unemployed     24     35.3%     36     52.9%     8     11.8%     68     7%       Other     24     44.4%     18     33.3%     12     22.2%     54     6%       Student     18     46.2%     14     35.9%     7     7.79%     39     4%       Retired     10     58.8%     4     23.5%     3     17.6%     17     2%       Insurance      79     50.6%     60     36.5%     17     10.9%     156     16%       No health insurance     79     50.6%     60     36.8%     41     27.0%     152     15%       Other     13     41.9%     15     48.4%     3     9.7%     31     3%       Other     13     41.9%     15     48.4%     2     22.2%     9     1%       Geography     5     33.3%     4     44.4%     2     22.2%     9     1%       Suburban     158     51.3%     112	Disabled	45	49.5%	41	45.1%	5	5.5%	91	10%
$\begin{array}{c c c c c c c c c c c c c c c c c c c $	Unemployed	24	35.3%	36	52.9%	8	11.8%	68	7%
Student1846.2%1435.9%717.9%394%Retired1058.8%423.5%317.6%172%Insurance12.8%423.5%317.6%172%Private insurance23451.2%16836.8%5512.0%45746%Medicare/Medicaid8541.5%9345.4%2713.2%20521%National insurance7950.6%6038.5%1710.9%15215%Other1341.9%1548.4%39.7%313%Indian Health Service333.3%444.4%222.2%91%Geography333.3%444.4%222.2%91%Suburban17046.4%13737.4%5916.1%36639%39%Urban15851.3%11236.4%3812.3%30833%Country33.148.7%23935.2%10916.1%67972%North American33.148.7%23935.2%10916.1%67972%North American33.148.7%23935.2%10916.1%67972%North American33.148.7%23935.2%10916.1%67972%New Zealand Australia <td>Other</td> <td>24</td> <td>44.4%</td> <td>18</td> <td>33.3%</td> <td>12</td> <td>22.2%</td> <td>54</td> <td>6%</td>	Other	24	44.4%	18	33.3%	12	22.2%	54	6%
Retired     10     58.8%     4     23.5%     3     17.6%     17     2%       Insurance	Student	18	46.2%	14	35.9%	7	17.9%	39	4%
Insurance     Private insurance     234     51.2%     168     36.8%     55     12.0%     457     46%       Medicare/Medicaid     85     41.5%     93     45.4%     27     13.2%     205     21%       National insurance     79     50.6%     60     38.5%     17     10.9%     156     16%       No health insurance     55     36.2%     56     36.8%     41     27.0%     152     15%       Other     13     41.9%     15     48.4%     3     9.7%     31     3%       Indian Health Service     3     33.3%     4     44.4%     2     22.2%     9     1%       Geography     Suburban     170     46.4%     137     37.4%     59     16.1%     366     39%       Urban     158     51.3%     112     36.4%     38     12.3%     308     33%       Rural     110     40.6%     118     43.5%     43     15.9%     271     28.7%	Retired	10	58.8%	4	23.5%	3	17.6%	17	2%
Private insurance     234     51.2%     168     36.8%     55     12.0%     457     46%       Medicare/Medicaid     85     41.5%     93     45.4%     27     13.2%     205     21%       National insurance     79     50.6%     60     38.5%     17     10.9%     156     16%       No health insurance     55     36.2%     56     36.8%     41     27.0%     152     15%       Other     13     41.9%     15     48.4%     3     9.7%     31     3%       Indian Health Service     3     33.3%     4     44.4%     2     22.2%     9     1%       Geography	Insurance								
Medicare/Medicaid     85     41.5%     93     45.4%     27     13.2%     205     21%       National insurance     79     50.6%     60     38.5%     17     10.9%     156     16%       No health insurance     55     36.2%     56     36.8%     41     27.0%     152     15%       Other     13     41.9%     15     48.4%     3     9.7%     31     3%       TRICARE/Veterans     8     42.1%     8     42.1%     3     15.8%     19     2%       Indian Health Service     3     33.3%     4     44.4%     2     22.2%     9     1%       Geography     Stubrban     170     46.4%     137     37.4%     59     16.1%     366     39%       Urban     158     51.3%     112     36.4%     38     12.3%     308     33%       Country     North American     331     48.7%     239     35.2%     109     16.1%     679     72%  <	Private insurance	234	51.2%	168	36.8%	55	12.0%	457	46%
National insurance     79     50.6%     60     38.5%     17     10.9%     156     16%       No health insurance     55     36.2%     56     36.8%     41     27.0%     152     15%       Other     13     41.9%     15     48.4%     3     9.7%     31     3%       TRICARE/Veterans     8     42.1%     8     42.1%     3     15.8%     19     2%       Indian Health Service     3     33.3%     4     44.4%     2     22.2%     9     1%       Geography     5     158     51.3%     112     36.4%     38     12.3%     308     33%       Rural     110     40.6%     118     43.5%     43     15.9%     271     28.7%       Country     73     35.6%     110     53.7%     22     10.7%     205     22%       Asia     3     25.0%     6     50.0%     1     10.0%     4     40.0%     10     1% <td< td=""><td>Medicare/Medicaid</td><td>85</td><td>41.5%</td><td>93</td><td>45.4%</td><td>27</td><td>13.2%</td><td>205</td><td>21%</td></td<>	Medicare/Medicaid	85	41.5%	93	45.4%	27	13.2%	205	21%
No health insurance     55     36.2%     56     36.8%     41     27.0%     152     15%       Other     13     41.9%     15     48.4%     3     9.7%     31     3%       TRICARE/Veterans     8     42.1%     8     42.1%     3     15.8%     19     2%       Indian Health Service     3     33.3%     4     44.4%     2     22.2%     9     1%       Geography     Suburban     170     46.4%     137     37.4%     59     16.1%     366     39%       Urban     158     51.3%     112     36.4%     38     12.3%     308     33%       Country     10     40.6%     118     43.5%     43     15.9%     271     28.7%       Country     331     48.7%     239     35.2%     109     16.1%     679     72%       Europe     73     35.6%     110     53.7%     22     10.7%     205     22%       Asia     3	National insurance	79	50.6%	60	38.5%	17	10.9%	156	16%
Other     13     41.9%     15     48.4%     3     9.7%     31     3%       TRICARE/Veterans     8     42.1%     8     42.1%     3     15.8%     19     2%       Indian Health Service     3     33.3%     4     44.4%     2     22.2%     9     1%       Geography     Suburban     170     46.4%     137     37.4%     59     16.1%     366     39%       Urban     158     51.3%     112     36.4%     38     12.3%     308     33%       Rural     110     40.6%     118     43.5%     43     15.9%     271     28.7%       Country     Trait     48.7%     239     35.2%     109     16.1%     679     72%       Europe     73     35.6%     110     53.7%     22     10.7%     205     22%       Asia     3     25.0%     1     10.0%     4     40.0%     10     1%       New Zealand/Australia     11	No health insurance	55	36.2%	56	36.8%	41	27.0%	152	15%
TRICARE/Veterans     8     42.1%     8     42.1%     3     15.8%     19     2%       Indian Health Service     3     33.3%     4     44.4%     2     22.2%     9     1%       Geography	Other	13	41.9%	15	48.4%	3	9.7%	31	3%
Indian Health Service     3     33.3%     4     44.4%     2     22.2%     9     1%       Geography     Suburban     170     46.4%     137     37.4%     59     16.1%     366     39%       Urban     158     51.3%     112     36.4%     38     12.3%     308     33%       Rural     110     40.6%     118     43.5%     43     15.9%     271     28.7%       Country     North American     331     48.7%     239     35.2%     109     16.1%     679     72%       Europe     73     35.6%     110     53.7%     22     10.7%     205     22%       Asia     3     25.0%     6     50.0%     3     25.0%     12     1%       Africa     3     50.0%     1     10.0%     4     40.0%     10     1%       Central/South America/Caribbean     3     50.0%     2     33.3%     0     0.0%     6     1%       Other	TRICARE/Veterans	8	42.1%	8	42.1%	3	15.8%	19	2%
Geography     Suburban     170     46.4%     137     37.4%     59     16.1%     366     39%       Urban     158     51.3%     112     36.4%     38     12.3%     308     33%       Rural     110     40.6%     118     43.5%     43     15.9%     271     28.7%       Country     North American     331     48.7%     239     35.2%     109     16.1%     679     72%       Lurope     73     35.6%     110     53.7%     22     10.7%     205     22%       Asia     3     25.0%     6     50.0%     3     25.0%     12     1%       Africa     5     50.0%     1     10.0%     4     40.0%     10     1%       New Zealand/Australia     11     44.0%     10     40.0%     4     16.0%     25     3%       Other     4     66.7%     2     33.3%     0     0.00%     6     1%       Participant-reported Hurley stag	Indian Health Service	3	33.3%	4	44.4%	2	22.2%	9	1%
Suburban     170     46.4%     137     37.4%     59     16.1%     366     39%       Urban     158     51.3%     112     36.4%     38     12.3%     308     33%       Rural     110     40.6%     118     43.5%     43     15.9%     271     28.7%       Country     North American     331     48.7%     239     35.2%     109     16.1%     679     72%       Loope     73     35.6%     110     53.7%     22     10.7%     205     22%       Asia     3     25.0%     6     50.0%     3     25.0%     10     1%       Central/South America/Caribbean     3     50.0%     1     10.0%     4     40.0%     10     1%       New Zealand/Australia     11     44.0%     10     40.0%     4     16.0%     25     3%       Other     4     66.7%     2     33.3%     0     0.0%     6     1%       Delay in diagnosis, years, median (I	Geography								
Urban     158     51.3%     112     36.4%     38     12.3%     308     33%       Rural     110     40.6%     118     43.5%     43     15.9%     271     28.7%       Country	Suburban	170	46.4%	137	37.4%	59	16.1%	366	39%
Rural11040.6%11843.5%4315.9%27128.7%CountryNorth American33148.7%23935.2%10916.1%67972%Europe7335.6%11053.7%2210.7%20522%Asia325.0%650.0%325.0%121%Africa550.0%110.0%440.0%101%Central/South America/Caribbean350.0%233.3%116.7%61%New Zealand/Australia1144.0%1040.0%416.0%253%Other466.7%233.3%00.0%61%Delay in diagnosis, years, median (IQR)11.5 (3–15)13 (3–16)9 (3–12.75)12 (3–15)Participant-reported Hurley stage2237.9%2543.1%1119.0%587%Stage 12237.9%2543.1%1119.0%587%Stage 222845.5%19639.1%7715.4%50157%Stage 316753.0%11034.9%3812.1%31536%	Urban	158	51.3%	112	36.4%	38	12.3%	308	33%
Country     North American     331     48.7%     239     35.2%     109     16.1%     679     72%       Europe     73     35.6%     110     53.7%     22     10.7%     205     22%       Asia     3     25.0%     6     50.0%     3     25.0%     12     1%       Africa     5     50.0%     1     10.0%     4     40.0%     10     1%       Central/South America/Caribbean     3     50.0%     2     33.3%     1     16.7%     6     1%       New Zealand/Australia     11     44.0%     10     40.0%     4     66.7%     2     33.3%     0     0.0%     6     1%       Delay in diagnosis, years, median (IQR)     11.5 (3–15)     13 (3–16)     9 (3–12.75)     12 (3–15)     12 (3–15)       Participant-reported Hurley stage     2     37.9%     25     43.1%     11     19.0%     58     7%       Stage 1     22     37.9%     25     43.1%     11     19.0%	Rural	110	40.6%	118	43.5%	43	15.9%	271	28.7%
North American     331     48.7%     239     35.2%     109     16.1%     679     72%       Europe     73     35.6%     110     53.7%     22     10.7%     205     22%       Asia     3     25.0%     6     50.0%     3     25.0%     12     1%       Africa     5     50.0%     1     10.0%     4     40.0%     10     1%       Central/South America/Caribbean     3     50.0%     2     33.3%     1     16.7%     6     1%       New Zealand/Australia     11     44.0%     10     40.0%     4     16.0%     25     3%       Other     4     66.7%     2     33.3%     0     0.0%     6     1%       Delay in diagnosis, years, median (IQR)     11.5 (3–15)     13 (3–16)     9 (3–12.75)     12 (3–15)     12 (3–15)       Participant-reported Hurley stage     2     37.9%     25     43.1%     11     19.0%     58     7%       Stage 1     22     37.9	Country								
Europe     73     35.6%     110     53.7%     22     10.7%     205     22%       Asia     3     25.0%     6     50.0%     3     25.0%     12     1%       Africa     5     50.0%     1     10.0%     4     40.0%     10     1%       Central/South America/Caribbean     3     50.0%     2     33.3%     1     16.7%     6     1%       New Zealand/Australia     11     44.0%     10     40.0%     4     16.0%     25     3%       Other     4     66.7%     2     33.3%     0     0.0%     6     1%       Delay in diagnosis, years, median (IQR)     11.5 (3–15)     13 (3–16)     9 (3–12.75)     12 (3–15)     12 (3–15)       Participant-reported Hurley stage     -     -     -     9 (3–12.75)     12 (3–15)       Stage 1     22     37.9%     25     43.1%     11     19.0%     58     7%       Stage 2     228     45.5%     196     39.1%     77<	North American	331	48.7%	239	35.2%	109	16.1%	679	72%
Asia     3     25.0%     6     50.0%     3     25.0%     12     1%       Africa     5     50.0%     1     10.0%     4     40.0%     10     1%       Central/South America/Caribbean     3     50.0%     2     33.3%     1     16.7%     6     1%       New Zealand/Australia     11     44.0%     10     40.0%     4     16.0%     25     3%       Other     4     66.7%     2     33.3%     0     0.0%     6     1%       Delay in diagnosis, years, median (IQR)     11.5 (3–15)     13 (3–16)     9 (3–12.75)     12 (3–15)     12 (3–15)       Participant-reported Hurley stage	Europe	73	35.6%	110	53.7%	22	10.7%	205	22%
Africa     5     50.0%     1     10.0%     4     40.0%     10     1%       Central/South America/Caribbean     3     50.0%     2     33.3%     1     16.7%     6     1%       New Zealand/Australia     11     44.0%     10     40.0%     4     16.0%     25     3%       Other     4     66.7%     2     33.3%     0     0.0%     6     1%       Delay in diagnosis, years, median (IQR)     11.5 (3–15)     13 (3–16)     9 (3–12.75)     12 (3–15)       Participant-reported Hurley stage     5     37.9%     25     43.1%     11     19.0%     58     7%       Stage 1     22     37.9%     25     43.1%     11     19.0%     58     7%       Stage 2     228     45.5%     196     39.1%     77     15.4%     501     57%       Stage 3     167     53.0%     110     34.9%     38     12.1%     315     36%	Asia	3	25.0%	6	50.0%	3	25.0%	12	1%
Central/South America/Caribbean     3     50.0%     2     33.3%     1     16.7%     6     1%       New Zealand/Australia     11     44.0%     10     40.0%     4     16.0%     25     3%       Other     4     66.7%     2     33.3%     0     0.0%     6     1%       Delay in diagnosis, years, median (IQR)     11.5 (3–15)     13 (3–16)     9 (3–12.75)     12 (3–15)       Participant-reported Hurley stage     53.0%     25     43.1%     11     19.0%     58     7%       Stage 1     22     37.9%     25     43.1%     11     19.0%     58     7%       Stage 2     228     45.5%     196     39.1%     77     15.4%     501     57%       Stage 3     167     53.0%     110     34.9%     38     12.1%     315     36%	Africa	5	50.0%	1	10.0%	4	40.0%	10	1%
New Zealand/Australia     11     44.0%     10     40.0%     4     16.0%     25     3%       Other     4     66.7%     2     33.3%     0     0.0%     6     1%       Delay in diagnosis, years, median (IQR)     11.5 (3–15)     13 (3–16)     9 (3–12.75)     12 (3–15)       Participant-reported Hurley stage     Stage 1     22     37.9%     25     43.1%     11     19.0%     58     7%       Stage 2     228     45.5%     196     39.1%     77     15.4%     501     57%       Stage 3     167     53.0%     110     34.9%     38     12.1%     315     36%	Central/South America/Caribbean	3	50.0%	2	33.3%	1	16.7%	6	1%
Other     4     66.7%     2     33.3%     0     0.0%     6     1%       Delay in diagnosis, years, median (IQR)     11.5 (3–15)     13 (3–16)     9 (3–12.75)     12 (3–15)       Participant-reported Hurley stage     5tage 1     22     37.9%     25     43.1%     11     19.0%     58     7%       Stage 2     228     45.5%     196     39.1%     77     15.4%     501     57%       Stage 3     167     53.0%     110     34.9%     38     12.1%     315     36%	New Zealand/Australia	11	44.0%	10	40.0%	4	16.0%	25	3%
Delay in diagnosis, years, median (IQR)     11.5 (3–15)     13 (3–16)     9 (3–12.75)     12 (3–15)       Participant-reported Hurley stage     22     37.9%     25     43.1%     11     19.0%     58     7%       Stage 1     22     37.9%     25     43.1%     11     19.0%     58     7%       Stage 2     228     45.5%     196     39.1%     77     15.4%     501     57%       Stage 3     167     53.0%     110     34.9%     38     12.1%     315     36%	Other	4	66.7%	2	33.3%	0	0.0%	6	1%
Participant-reported Hurley stage     22     37.9%     25     43.1%     11     19.0%     58     7%       Stage 1     22     37.9%     25     43.1%     11     19.0%     58     7%       Stage 2     228     45.5%     196     39.1%     77     15.4%     501     57%       Stage 3     167     53.0%     110     34.9%     38     12.1%     315     36%	Delay in diagnosis, years, median (IOB)	11.5 (3–15)	00.170	13 (3-16	)	9 (3-12.75)	0.070	12 (3-15)	170
Stage 1     22     37.9%     25     43.1%     11     19.0%     58     7%       Stage 2     228     45.5%     196     39.1%     77     15.4%     501     57%       Stage 3     167     53.0%     110     34.9%     38     12.1%     315     36%	Participant-reported Hurley stade				/	5 (6 .20)		. 2 (8 10)	
Stage 2     228     45.5%     196     39.1%     77     15.4%     501     57%       Stage 3     167     53.0%     110     34.9%     38     12.1%     315     36%	Stage 1	22	37.9%	25	43.1%	11	19.0%	58	7%
State 3 167 53.0% 110 34.9% 38 12.1% 315 36%	Stage 2	228	45.5%	196	39.1%	77	15.4%	501	57%
	Stage 3	167	53.0%	110	34.9%	38	12.1%	315	36%

% denotes the percentage of cohort participants that have the specified HS provider type.

HS, hidradenitis suppurativa; IQR, interquartile range; n, number of participants in each group.

n = 94/440; nondermatologist: 15.6%, n = 55/353; no provider: 16.7%, n = 23/138) and insurance authorization (dermatologist: 15.7%, n = 69/440; nondermatologist: 13.6%, n = 48/353; no provider: 13.8%, n = 19/138) were also barriers reported across all provider types. Cost of care was a frequent barrier among all groups, but most frequently reported among those with no provider (no provider: 37.7%, n = 52/138; dermatologist provider: 29.5%, n = 130/440; nondermatologist: 27.8%, n = 98/353).

Overall, 74.2% (n = 663/894) of our cohort reported experiencing stigma while accessing care for their HS. The most common sources of stigma reported were weight (59.1%, n = 528/894), location of HS lesions (34.9%, n = 312/894), and

smoking status (32.7%, n = 292/894). Sources of stigma had limited variability across provider types (Fig. 3).

## Discussion

Our study provides novel data about the demographic characteristics, disease characteristics, management, and barriers to care experienced by individuals with HS who do not report a dermatologist as their primary HS provider. Because nearly half of our study participants were not connected with dermatologic care, our findings provide a unique and inclusive perspective into barriers faced by HS patients across the spectrum of HS health

Table 2				
Comorbid (	conditions among	cohort participa	nts by self-report	ed Hurlev stage

	All		Hurley stage 1		Hurley stage 2		Hurley stage 3	
	n = 927	%	<i>n</i> = 58	%	<i>n</i> = 500	%	<i>n</i> = 315	%
Anxiety	518	55.9%	35	60.3%	270	54.0%	188	59.7%
Obesity	470	50.7%	32	55.2%	247	49.4%	166	52.7%
Depression	497	53.6%	29	50.0%	259	51.8%	187	59.4%
Acne	335	36.1%	20	34.5%	191	38.2%	104	33.0%
Polycystic ovarian syndrome	194	20.9%	14	24.1%	104	20.8%	71	22.5%
Hypertension	185	20.0%	12	20.7%	91	18.2%	70	22.2%
Hyperlipidemia	125	13.5%	10	17.2%	62	12.4%	44	14.0%
Thyroid disease	102	11.0%	9	15.5%	44	8.8%	43	13.7%
Suicidal ideation	129	13.9%	6	10.3%	69	13.8%	49	15.6%
Type 2 diabetes	109	11.8%	4	6.9%	43	8.6%	53	16.8%
Alcohol or substance use disorder	90	9.7%	6	10.3%	46	9.2%	31	9.8%
Spondyloarthritis	57	6.1%	3	5.2%	22	4.4%	27	8.6%
Sexual dysfunction	26	2.8%	2	3.4%	14	2.8%	9	2.9%
Coronary artery disease	8	0.9%	1	1.7%	5	1.0%	1	0.3%
Disability related to your HS	75	8.1%	1	1.7%	20	4.0%	51	16.2%
Rheumatoid arthritis	42	4.5%	0	0.0%	22	4.4%	20	6.3%
Crohn disease or ulcerative colitis	34	3.7%	1	1.7%	15	3.0%	15	4.8%
Myocardial infarction	9	1.0%	0	0.0%	5	1.0%	4	1.3%
Lupus	7	0.8%	0	0%	3	0.6%	4	1.3%

% denotes the percentage of participants in each Hurley stage that have the specified comorbid condition.

HS, hidradenitis suppurativa; *n*, number of participants in each group.

care access. We found that Asian race, full-time employment, private health insurance, and urban setting were each associated with higher rates of having a dermatologist as a primary HS provider. Having a dermatologist as the primary HS provider was also associated with increased frequency of biologics prescription for HS compared with other provider types. Our cohort was notably more severely impacted by comorbid diseases such as anxiety, obesity, and depression compared with reports from previous HS survey studies.<sup>1</sup> Participants reported significant barriers to care including lack of treatment options,





**Fig. 1.** Participant-reported HS treatments ever prescribed by HS primary provider type (*n* = 927). <sup>1</sup>Chlorhexidine, benzoyl peroxide, bleach baths. <sup>2</sup>Topical clindamycin, topical metronidazole, topical steroids, etc. <sup>3</sup>Oral contraceptives, spironolactone, etc. <sup>4</sup>Adalimumab, infliximab, etc. <sup>5</sup>Cyclosporine, apremilast, etc. DMARDs, disease-modifying antirheumatic drugs; HS, hidradenitis suppurativa; IV, intravenous.





limited provider knowledge, and sources of stigma, regardless of provider type.

Our study findings also provide novel information about sources of stigma that individuals with HS, particularly women with HS, encounter during medical appointments. Previous studies have focused on sources of internalized stigma in HS patients<sup>5,10,11</sup>; however, there is limited data on the sources of stigma HS patients endure while trying to access care. Our study



Fig. 3. Participant-reported sources of stigma experienced when accessing HS care by HS primary provider type (n = 894). HS, hidradenitis suppurativa.

found that obesity and smoking were major sources of stigma among our cohort. Additionally, socioeconomic status (8.5%), race (7.2%), and gender (8.8%) were also cited as sources of stigma in our cohort and their frequencies did not differ across provider types, suggesting that social determinants of health and patient background may play a role in access to care. Increased provider awareness of patient-perceived sources of stigma may help to change approach in managing HS and its comorbidities and improve overall care.

Our study found that access to dermatology differed by race. American Indian/Alaskan Native participants more commonly reported no provider and less commonly had a dermatologist provider for their HS when compared with other races. The majority of American Indian/Alaskan Native participants reported living in rural areas.<sup>12</sup> These populations may have limited access to dermatology as less than 10% of dermatologists practice in rural areas and of all the 26 US counties with a Native American majority, all have zero dermatologists within the county.<sup>13,14</sup> Limited access to dermatology services via Indian Health Services may be another contributor.

We found that individuals with full-time employment and those with private insurance more commonly had a dermatology provider for their HS compared with those with other employment and insurance types. Higher annual household income may translate to increased access to HS care through insurance, proximity to dermatologist, or ability to pay for specialty care. This finding is also supported by previous research, which shows that those with private insurance visit dermatologists more frequently and have shorter wait times to see dermatologists compared with those with public insurance in the United States.<sup>15,16</sup>

Based on our data, country of residence also appeared to impact access to a dermatologist for HS care. Respondents from Europe more commonly had a nondermatologist HS provider. About 73.6% of European participants were from the UK where the National Health Service requires a referral from primary care providers for specialist care. Data from 2022 found that 62.6% of UK residents referred to a specialist had started specialist treatment by 18 weeks,<sup>17</sup> which is longer compared with the United States in which the average time to see a specialist is 26 days (34.5 days to see a dermatologist).<sup>18</sup> Seventy-eight percentage of Europeans in our study who received biologics had a dermatologist as their HS provider. Given that nondermatologists are much less likely to prescribe biologics than dermatologists in Europe, access to a specialist is likely very important for timely HS care.

Interestingly, we found that participants who did not have a current HS provider had the shortest delay in diagnostic time (9 years) compared with 11.5 years among those with a dermatologist provider and 13 years among those with a nondermatologist provider. This finding does not reflect if a dermatologist diagnosed an individual with HS, but rather whether they were currently in the care of a dermatologist at the time of survey completion. One possibility for this finding is that those without a provider are more likely to self-diagnose and report time of diagnosis earlier than when self-diagnosis was confirmed by a provider.

The only Food and Drug Administration approved treatment for moderate to severe HS currently is the tumor necrosis factor inhibitor, adalimumab.<sup>19</sup> While 93% of our cohort self-reported Hurley stage 2 or 3 HS, only 26.9% of our cohort had been prescribed biologics. Among those with a dermatologist as their primary HS provider, 43.7% had been prescribed a biologic for their HS. This percentage is greater compared with the Global Voice (GV) study, which found that 20.8% of their cohort was treated with biologics, suggesting increased adoption of adalimumab since 2017 when GV was conducted.<sup>1</sup> As GV participants did not comment on disease severity, the difference in biologic use frequencies may also be due to a lower proportion of participants with moderate and severe disease. Despite limited evidence, topical cleansers and antiseptics are recommended in 3 HS management guidelines<sup>20-22</sup> and 82.5% of participants with dermatologists in our study were prescribed these treatments. About 92.9% of participants with dermatologists were prescribed antibiotics, which is notable as previous studies have reported that dermatologists prescribe antibiotics at a higher rate than any other specialty.<sup>23</sup> Although there is limited data to support the efficacy of home remedies and dietary modifications for HS,<sup>24</sup> over one-third of our respondents used diet modification for HS management regardless of provider types.

Our cohort reported significant burden of comorbid disease: 55.9% of study participants reported anxiety compared with 36.2% of GV participants. Study participants also reported increased rates of depression (53.6%; GV: 35%), SI (13.9%; GV: 7.9%), and polycystic ovary syndrome (20.9%; GV: 14.2%) compared with the GV cohort. These proportions are also greater than those of the general population in the United States, where 31.1% of adults report anxiety, 8.4% report major depression, and 4.3% report SI.<sup>25–27</sup> Taken together, these data suggest that those who do not receive HS care from a dermatologist may have limited access to care overall. Notably, we found that frequency of mental health comorbidities increased with disease severity, indicating that accessible mental health services for those with moderate and severe HS may be an important component of overall care for HS patients.

The most common barrier to HS care reported was lack of treatment options (54.1%), which is unsurprising as there is currently only one Food and Drug Administration approved drug for HS and it is not uniformly effective for all people with HS. Novel agents are under investigation and offer hope for improved HS management. The second most common barrier reported regardless of provider type was provider knowledge, reported by 50.3% of study participants, including 44.5% of those with a dermatologist. This finding suggests that patients perceive limited provider knowledge about HS even among dermatologists. A qualitative study with individuals with HS found that they experienced emotional burden of perceived stigma and shame during health care interactions, a desire to be treated with respect, and a need for clear communication even if it meant health care providers acknowledged their knowledge gaps.<sup>5</sup> One explanation for our findings is that poor patient-physician rapport is exacerbated by HS-associated stigma and poor communication, which may result in patients perceiving that their provider was not knowledgeable about their condition.

#### Limitations

The major strength of this study is that it reports the experiences of a large, global, racially and ethnically diverse group of individuals with HS along the full spectrum of access to a dermatologist or other health care provider. This study has limitations as well. The survey was conducted via Facebook and other online HS support groups to reach individuals with HS who do not access medical care; however, this recruitment approach may introduce selection bias and favor well-resourced areas. Data was self-reported and may be subject to recall bias.

#### Conclusions

Our study provides unique insights into the characteristics and experiences of individuals with HS across the spectrum of health care access. Our data suggest that North Americans, those with private insurance, full-time employment, and in urban areas, more frequently had access to dermatologist HS care. Those with dermatologist HS care more frequently had access to biologic therapies. Limited access to health care with a dermatologist or nondermatologist provider may limit care of HS and associated comorbidities, including mental health disorders. Barriers to care and stigma were prevalent among survey respondents regardless of HS provider type. Future studies aimed at understanding access to HS care among men are warranted.

## **Conflicts of interest**

H.B.N. has received grant support from AbbVie; consulting fees from 23andme, AbbVie, Aristea Therapeutics, Nimbus Therapeutics, Medscape and DAVA Oncology, Boehringer Ingelheim, UCB, and Novartis; investigator fees from Pfizer; and has shares in Radera, Inc. She is also an Associate Editor for JAMA Dermatology and a Board Member of the Hidradenitis Suppurativa Foundation. The other author has no conflicts of interest to disclose.

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#### Study approval

N/A

# **Author contributions**

F-ABR and HBN: Participated in research design, writing the manuscript, performance of research, and data analysis.

## References

- Garg A, Neuren E, Cha D, et al. Evaluating patients' unmet needs in hidradenitis suppurativa: results from the Global Survey of Impact and Healthcare Needs (VOICE) project. J Am Acad Dermatol 2020;82:366–76.
- Kirby JS, Leiphart P. Standing up together to the shame and stigma associated with hidradenitis suppurativa. Br J Dermatol 2020;182:267–8.
- Alavi A, Anooshirvani N, Kim WB, Coutts P, Sibbald RG. Quality-of-life impairment in patients with hidradenitis suppurativa: a Canadian study. Am J Clin Dermatol 2015;16:61–5.
- Garg A, Kirby JS, Lavian J, Lin G, Strunk A. Sex- and age-adjusted population analysis of prevalence estimates for hidradenitis suppurativa in the United States. JAMA Dermatol 2017;153:760–4.
- Barnes LA, Shukla N, Paul M, et al. Patient perspectives of health system barriers to accessing care for hidradenitis suppurativa: a qualitative study. JAMA Dermatol 2023;159:510–7.
- Saunte DML, Jemec GBE. Hidradenitis suppurativa: advances in diagnosis and treatment. JAMA 2017;318:2019–32.
- Kokolakis G, Wolk K, Schneider-Burrus S, et al. Delayed diagnosis of hidradenitis suppurativa and its effect on patients and healthcare system. Dermatology 2020;236:421–30.
- Shukla N, Paul M, Halley M, et al. Identifying barriers to care and research in hidradenitis suppurativa: findings from a patient engagement event. Br J Dermatol 2020;182:1490–1492.

- Zouboulis CC, Desai N, Emtestam L, et al. European S1 guideline for the treatment of hidradenitis suppurativa/acne inversa. J Eur Acad Dermatol Venereol 2015;29:619–44.
- Kirby JS, Leiphart P. Standing up together to the shame and stigma associated with hidradenitis suppurativa. Br J Dermatol 2020;182:267–8.
- Koumaki D, Efthymiou O, Bozi E, Katoulis AC. Perspectives on perceived stigma and self-stigma in patients with hidradenitis suppurativa. Clin Cosmet Investig Dermatol 2019;12:785–90.
- Dewees S, Marks B. Twice invisible: understanding rural native America. Albuquerque, NM: First Nations Development Institute; 2017.
- Vaidya T, Zubritsky L, Alikhan A, Housholder A. Socioeconomic and geographic barriers to dermatology care in urban and rural US populations. J Am Acad Dermatol 2018;78:406–8.
- Hooper J, Shao K, Feng H. Racial/ethnic health disparities in dermatology in the United States, part 1: overview of contributing factors and management strategies. J Am Acad Dermatol 2022;87:723–30.
- Hogue CJR, Hargraves MA, Collins KS. Minority health in America: findings and policy implications from the Commonwealth Fund Minority Health Survey. Baltimore, MD: Johns Hopkins University Press; 2000.
- Harvey V, Paul J. Racial and Ethnic Disparities in Dermatology Office Visits among Insured Patients, 2005-2010. J Health Disparities Res Pract 2016;9:93–131.
- Levell NJ. NHS outpatient secondary care: a time of challenges and opportunities. Future Healthc J 2022;9:106–12.
- Merritt Hawkins. Wait times and Medicare and Medicaid acceptance rates. n.d. Available from: https://www.merritthawkins.com/uploaded-Files/MerrittHawkins/Content/News\_and\_Insights/Articles/mha-2022wait-time-survey.pdf.
- Bi, Y, Liu, J, Wang, J, et al. Model-informed drug development approach supporting approval of adalimumab (HUMIRA) in adolescent patients with hidradenitis suppurativa: a regulatory perspective. AAPS J 2019;21:1–6.
- Hunger RE, Laffitte E, Läuchli S, et al. Swiss practice recommendations for the management of hidradenitis suppurativa/acne inversa. Dermatology 2017;233:113–9.
- Magalhães RF, Rivitti-Machado MC, Duarte GV, et al. Consensus on the treatment of hidradenitis suppurativa - Brazilian Society of Dermatology. An Bras Dermatol 2019;94:7–19.
- 22. Alikhan A, Sayed C, Alavi A, et al. North American clinical management guidelines for hidradenitis suppurativa: a publication from the United States and Canadian Hidradenitis Suppurativa Foundations: Part II: topical, intralesional, and systemic medical management. J Am Acad Dermatol 2019;81:91–101.
- Barbieri JS, Bhate K, Hartnett KP, Fleming-Dutra KE, Margolis DJ. Trends in oral antibiotic prescription in dermatology, 2008 to 2016. JAMA Dermatol 2019;155:290–7.
- Silfvast-Kaiser A, Youssef R, Paek SY. Diet in hidradenitis suppurativa: a review of published and lay literature. Int J Dermatol 2019;58:1225–30.
- 25. U.S. Department of Health and Human Services. Anxiety disorder. National Institute of Mental Health; n.d. Available from: https://www. nimh.nih.gov/health/statistics/any-anxiety-disorder.
- U.S. Department of Health and Human Services. Major depression. National Institute of Mental Health; n.d. Available from: https://www. nimh.nih.gov/health/statistics/major-depression.
- 27. Centers for Disease Control and Prevention. Suicidal thoughts and behaviors among adults aged ≥18 years United States, 2015–2019. Centers for Disease Control and Prevention; 2022. Available from: https://www.cdc.gov/mmwr/volumes/71/ss/ss7101a1.htm.