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Barriers to Dermatologic Care and Use of Internet Sources in Hidradenitis Suppurativa

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INTRODUCTION

Although hidradenitis suppurativa (HS) often requires multidisciplinary care, dermatologists specialize in the diagnosis and management of this condition. As HS is associated with low socioeconomic status, individuals may face barriers accessing dermatologic care due to financial and insurance challenges.[1,2] A qualitative study of HS participants noted that frustrations with delays in care may drive patients to use the Internet to learn about HS.[3] This study further evaluates barriers to dermatologic care and the use of internet sources amongst those with HS.

MATERIALS AND METHODS

An anonymous, 40-item, multiple-choice survey was distributed in HS-related online groups. Participants 18 years and older in the United States with a diagnosis of HS were included. Data were collected between August and September 2022 and analyzed with Microsoft Excel version 16.65. Chi-square tests were performed. The Northwestern University Institutional Review Board approved this study.

RESULTS

Overall, 302 participants completed the survey. Table 1 shows the characteristics of the respondents. Regarding the primary medical providers for management of their HS, 69.9% (211/302) reported seeing a dermatologist, 20.5% (62/302) reported seeing a non-dermatology provider, and 9.6% (29/302) reported not seeing any medical provider for their HS. Of those with a non-dermatology provider for their HS, 64.5% (40/62) reported seeing a primary care provider, 21.0% (13/62) reported seeing a surgeon, and 14.5% (9/62) reported seeing a gynecologist. Thirty-nine percent (82/211) of those with a dermatologist visited them yearly or less often. Over half of all respondents (51.3%, 155/302) reported that seeing the dermatologist is difficult or very difficult. Black (odds ratio [OR], 2.09; 95% CI, 1.20–3.66; *P*<0.01) and Medicaid-insured individuals (OR, 2.64; 95% CI, 1.44–4.85; *P*<0.01) were more likely to report difficulty than those who were White or had private insurance, respectively. Commonly reported barriers to seeing the dermatologist include long wait times to schedule appointments (59.6%, 180/302), financial/insurance challenges (24.2%, 73/302), HS-related pain hindering appointment attendance (23.8%, 72/302), work-related challenges (18.9%, 57/302), commute/transportation challenges (13.9%, 42/302), and inability to obtain referrals (7.3%, 22/302).

TABLE 1.

Characteristics of Survey Participants

Characteristic	No. (%)
Total	302
Gender	
Female	271 (89.7)
Male	31 (10.3)
Age, mean (SD)	37.5 (17.7)
Race/Ethnicity	
White	168 (55.6)
Black/African American	76 (25.2)
Hispanic/Latinx	33 (10.9)
Asian	7 (2.3)
Multiracial	12 (4.0)
Other	6 (2.0)
Education	
Less than high school	4 (1.3)
High school graduate	88 (29.1)
Occupational school	22 (7.3)
Bachelor's degree	133 (44.0)
Graduate degree	55 (18.2)
Household Income	
< $19,999	39 (12.9)
$20,000-$89,999	161 (53.1)
$90,000-$179,999	76 (25.2)
$180,000+	26 (8.6)
Frequency of Flares	
Once a month or more	169 (84.8)
Less than once a month	46 (15.2)
Insurance	
Private	186 (61.6)
Medicaid	64 (21.2)
Medicare	30 (9.9)
No insurance	22 (7.3)
Primary HS Provider	
Dermatologist	211 (69.9)
Non-dermatology Provider	62 (20.5)
No Provider	29 (9.6)

TABLE 2.

Use of Interest Sources Among Those With HS

Characteristic	No. (%)
Total Internet Users	225
Website	
Facebook	144 (64.0)
Google	131 (58.2)
HS-specific Organizations	113 (50.2)
Reddit	75 (33.3)
TikTok	39 (17.3)
YouTube	32 (14.2)
Instagram	7 (3.1)
Source of Information	
Others with HS	175 (77.8)
Medical professionals	50 (22.2)
Reasons for Using Internet Sources	
To better understand HS	167 (74.2)
To find a community of others with HS	164 (72.9)
To find alternative treatments or specific products	146 (64.9)
Internet is free and more accessible than a doctor	93 (41.3)
Not getting enough time with doctor	68 (30.2)
Want a second opinion besides a doctor	40 (17.8)

Most participants (74.5%, 225/302) reported using the internet to access information about HS, namely Facebook (64.0%, 144/225), Google (58.2%, 131/225), HS-specific organizations (50.2%, 113/225), and Reddit (33.3%, 75/225). Reasons for using internet sources included desires to better understand HS (74.2%, 167/225), find a community of others with HS (72.9%, 164/225), and learn about alternative treatments (64.9%, 146/225; Table 2). Thirty percent (68/225) reported using the internet as they do not get enough time with their doctor.

DISCUSSION

Among this cohort, one-third reported not seeing a dermatologist for their HS, and one-tenth reported not seeing any provider for their HS. Providers of other specialties need to ensure referrals to dermatology for HS patients who do not see a dermatologist. Of those that see a dermatologist, over one-third reported having visits yearly or less often, despite most of them having active disease with monthly flares. Many participants noted difficulties accessing dermatological care, particularly long wait times and financial and insurance challenges. HS disproportionately affects Black individuals,[4] and in this survey, Black participants were also more likely to report challenges seeking dermatologic care than White individuals. Medicaid-insured individuals similarly reported more difficulty accessing a dermatologist, consistent with a recent study that noted that Medicaid-insured patients face lower success and longer wait times in obtaining dermatology appointments than those with private insurance.[5] Teledermatology and increased access to safety-net providers may help decrease the disparities.

Additionally, internet use amongst those with HS is prevalent with many citing the internet as free and more accessible than a physician. The online community provides support to those with HS, especially since many may struggle with embarrassment or mental health.[6] These online sources can allow medical professionals to increase visibility of evidence-based recommendations and information about access to HS specialists. Many individuals reported using the internet for information since they do not get enough time with their doctor, suggesting that those with HS may also benefit from longer appointment lengths.

Study limitations include the low proportion of certain racial/ethnic groups and males; respondents from online support groups may not represent the general HS population. Nevertheless, these findings highlight the need to increase timely access to dermatologic care for those with HS and improve evidence-based content on online HS sources.

DISCLOSURES

The authors have no conflict of interest to declare.

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