Dear Editors,

Hidradenitis suppurativa (HS) is a chronic inflammatory dermatosis that disproportionately affects women in the United States. Patients may experience misdiagnoses or progressive disease before receiving an accurate diagnosis. Meeting patient needs in time-constrained clinic visits may be challenging for healthcare providers (HCPs). Herein, we characterize HS patient priorities during clinic visits.

An anonymous survey was distributed to 3 online HS support groups from October 2021 to January 2022. T tests assessed associations between demographics and Likert scale (1–5) responses. P < 0.05 was considered statistically significant.

Of 158 respondents, 92.4% were female. Demographics are reported in Table 1. Most respondents prepared questions (76.6%) and researched providers’ HS experience (53.2%) before their clinic visit. At initial visits, respondents prioritized discussing treatments (80.4%), symptoms (72.8%), and flare self-management (71.5%) (Fig. 1). At subsequent visits, respondents prioritized emotional well-being (64.6%) and treatment plans (61.4%). Only a quarter wished to discuss weight loss or sexual health at any visit.

About half (52.0%) would recommend their HS HCP to others. HS specialty clinic patients were more likely to do so (4.60 vs 3.42, P = 0.0001). About half (50.6%) limit asking questions to avoid being perceived as difficult; 47.3% downplay their symptoms. Respondents younger than 40 years old were more likely to limit questions (3.48 vs 2.59, P = 0.0004) and downplay symptoms (3.29 vs 2.61, P = 0.007). They were less likely to understand all of their HCP’s instructions (3.75 vs 4.32, P = 0.003). About half (50.6%) would like their HCP to counsel using multimedia resources; 12.7% reported their HCP did so.

Between visits, respondents valued receiving medication advice (77.9%), assistance in accessing medications (74.4%), scheduling appointments for flares (65.6%), and coordinating referrals (59.7%). Top patient education resources were online HS support groups (69.9%), professional organization websites (51.9%), and social media (43.7%). Most helpful resources were support groups (Likert scale, 4.42) and expert lectures (4.40).

Our study findings support a longitudinal approach to HS visits as opposed to attempting to address all HS-related topics in the first visit. Respondent results regarding the first visit are in line with Flood et al.’s guide to HS management that recommends discussion of disease, treatments, and flare management at baseline visits. Although the authors recommended diet/ exercise counseling and sexual health screening early in care, we recommend they be introduced with great sensitivity only after establishing rapport given low respondent interest in these topics.

HCPs should also be aware that patients may downplay their symptoms, particularly younger patients. Routinely asking about symptoms in a standardized manner (ie, pain on a numeric rating scale of 0–10) may help HCPs track the impact of treatments on patient symptoms. Incorporating photos, drawings, or videos into patient counseling may improve patient understanding. Finally, support group information is a key resource HCPs should routinely offer. Study limitations include self-reported HS disease severity and female-predominant responses.

Understanding HS patient preferences for clinic visits will allow HCPs to better meet patient expectations. HCPs should implement strategies to improve communication with patients, address patient needs between visits, and connect patients to valued educational resources.

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An anonymous survey was distributed with permission through online social media HS support groups with permission between October 2021 and January 2022.

Author contributions

TS, DRD, BB, DF, VYS, JLH: Designed the patient survey. TS: Analyzed the data and wrote the manuscript. DRD, VYS, JLH: Edited the manuscript. VYS, JLH: Led the project.

Conflicts of interest

Conflicts of Interest: J.L.H. is on the Board of Directors for the Hidradenitis Suppurativa Foundation, has served as a consultant for一家 pharmaceutical company, and has a patent pending.

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

• Hidradenitis suppurativa (HS) is a chronic, debilitating dermatosis that disproportionally affects women and imparts significant physical and psychosocial burdens.

• Given the complexity of HS and its comorbidities, meeting patient needs in time-constrained clinic visits may be challenging for healthcare providers. Patient priorities in HS clinic visits have yet to be explored.

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

• In our survey (92.4% women), respondents prioritized discussion of HS treatments and symptoms at the initial visit and emotional well-being and treatment plans at subsequent visits. Discussion of weight loss or sexual health should be introduced with great sensitivity only after establishing rapport.

• Younger respondents were more likely to limit asking questions and downplay their symptoms, highlighting opportunities for improved communication.

• Healthcare providers should implement strategies to address patient priorities during and between clinic visits.
Table 1. Respondent demographics and disease characteristics

| Demographics and disease characteristics | n (%) |
|-----------------------------------------|-------|
| Age (n = 158)                            | 40.80 ± 11.13 (range 18–64) |
| Age at start of HS symptoms (n = 158)   | 19.11 ± 8.86 (range 5–62)    |
| Age at diagnosis (n = 151)              | 32.03 ± 11.19 (range 13–63)  |
| Female gender (n = 158)                 | 146 (92.4%)                   |
| HS was diagnosed by healthcare provider (n = 158) | 151 (95.6%)                  |
| Receiving care at an HS specialty clinic (n = 158) | 17 (10.8%)                   |
| Race (n = 158)                           |                                 |
| White                                   | 123 (77.8%)                   |
| Black                                   | 14 (8.9%)                     |
| Hispanic/Latino                         | 11 (7.0%)                     |
| Asian/Pacific Islander                  | 6 (3.8%)                      |
| Bi- or multiracial                      | 2 (1.3%)                      |
| Other                                   | 2 (1.3%)                      |
| Hurley stage I, II, III (n = 156)a       | 13 (8.2%), 65 (41.1%), 78 (49.4%) |
| Education higher than high school (n = 158) | 133 (84.2%)                  |
| Country (n = 158)                       |                                 |
| United States                           | 143 (90.5%)                   |
| Canada                                  | 10 (6.3%)                     |
| Others b                                | 5 (3.2%)                      |
| Primary provider for HS (n = 158)       |                                 |
| Dermatologist                           | 103 (65.2%)                   |
| Primary care physician                  | 22 (13.9%)                    |
| Surgeon                                 | 9 (5.7%)                      |
| Obstetrician/gynecologist               | 6 (3.8%)                      |
| Nurse practitioner                      | 4 (2.5%)                      |
| Emergency medicine doctor               | 3 (1.9%)                      |
| Physician assistant                     | 1 (0.6%)                      |
| Rheumatologist                          | 1 (0.6%)                      |
| Other                                   | 6 (3.8%)                      |
| None                                    | 3 (1.9%)                      |

HS, hidradenitis suppurativa.

a Respondents self-reported their Hurley stage after reading written descriptions of each stage.

b Other countries include Ireland, Germany, and Puerto Rico.
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