

Patient Perspectives of Health System Barriers to Accessing Care for Hidradenitis Suppurativa

A Qualitative Study

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 [Supplemental content](#)

IMPORTANCE Patient-perceived barriers to hidradenitis suppurativa (HS) care are poorly understood. Understanding health care barriers is a critical first step toward improving care for this population.

OBJECTIVE To characterize the health care experiences of people living with HS, including perceived barriers and facilitators to health care access, and to elucidate potential associations among these barriers and facilitators, health care access, and disease activity.

DESIGN, SETTING, AND PARTICIPANTS In this qualitative study, an inductive thematic analysis was conducted on 45 in-depth, 60- to 90-minute semistructured interviews of 45 people with HS from diverse sociodemographic backgrounds that took place between March and April 2020. Individuals were eligible if they could speak English, were 18 years or older, and were diagnosed with HS. A diagnosis of HS was confirmed through physician diagnosis or through self-reported, affirmative response to the validated screening question, “Do you experience boils in your armpits or groin that recur at least every six months?”

MAIN OUTCOMES AND MEASURES Interviews were audio recorded and transcribed verbatim. A modified grounded theory approach was used to develop the codebook, which investigators used for inductive thematic analysis.

RESULTS Among the 45 participants included, the median (IQR) age was 37 (16) years, 33 (73%) were female, and 22 (49%) were White. There were 6 interrelated themes associated with participant-perceived barriers to accessing HS care: (1) bidirectional associations of disease activity and employment, (2) association of employment with health care coverage, (3) association of health care coverage with costs and perceived access to care, (4) association of costs with access to patient-centered care, (5) health care professional attitudes and knowledge influence patient-centered care and perceived access to care and disease activity, and (6) health system characteristics influence patient-centered care and associated costs, perceived access to care, and disease activity.

CONCLUSIONS AND RELEVANCE This qualitative study highlights themes that generate a conceptual model for understanding barriers that may act synergistically to limit health care access and influence disease activity. The disease activity of HS may be reduced when cycle elements are optimized. This study also highlights areas for future investigations and potential systems-level changes to improve access to patient-centered HS care.

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JAMA Dermatol. 2023;159(5):510-517. doi:10.1001/jamadermatol.2023.0486
Published online April 5, 2023.

Hidradenitis suppurativa (HS) is a painful and disfiguring chronic inflammatory skin disease associated with increased morbidity¹⁻⁴ and mortality⁵⁻⁷ that affects approximately 1% of the general US population, and it disproportionately affects women and Black Americans. People with HS face considerable challenges to health care access, with the average patient experiencing a diagnostic delay of 7 to 10 years.⁸ Additionally, poor understanding of HS biology has limited the development of effective treatments,⁹⁻¹² thereby contributing to substantial quality-of-life impairment.

Limited research has examined the experiences of people with HS seeking health care services. Based on a focus group of patient leaders of HS support communities on Facebook, we previously reported health care professional-related barriers to seeking clinical care and participating in research, including (1) practitioners' lack of knowledge about HS, (2) difficulty accessing specialists who are knowledgeable about HS, (3) poor communication, (4) patient distrust of the medical community, and (5) patients' experiences of HS.¹³ The current study uses systematic, in-depth qualitative interviews with people with HS to extend this work and examine potential associations between perceived barriers to and facilitators of patient-centered health care access and their association with patient-reported disease activity.

Methods

Study Design

We conducted an inductive thematic analysis of 45 in-depth interviews with people with HS. We developed a semistructured interview guide through literature review and pretesting with people with HS before study initiation. Interview questions addressed the following domains: (1) facilitators and barriers to HS care, (2) economic factors associated with HS care, (3) health care professional knowledge about HS, and (4) support.

Participants were individually interviewed via video conference between March and April 2020 by a study team member trained in qualitative interview methods (N.S.). Interviews lasted 60 to 90 minutes and were audio recorded, transcribed verbatim, and deidentified. Self-reported demographic characteristics, including age, gender, race and ethnicity, and annual household income, were collected.

This study was approved by the University of California, San Francisco and Stanford University institutional review boards. Informed consent was obtained from participants using a consent form developed with the University of California, San Francisco institutional review board. The study followed the Standards for Reporting Qualitative Research (SRQR) reporting guideline and the Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guideline for qualitative studies.^{14,15}

Participant Recruitment and Data Collection

Participants were recruited from institutional databases and from HS online communities to ensure demographic and socioeconomic diversity.¹⁶ Eligible participants were 18 years or older, spoke English, and had HS diagnosis confirmed via phy-

Key Points

Question What barriers to health care do people with hidradenitis suppurativa experience?

Findings In this qualitative study, 6 themes for barriers to care were identified: (1) bidirectional association of disease activity and employment, (2) association of employment with health care coverage, (3) association of health care coverage with costs and perceived access to care, (4) association of costs with access to patient-centered care, (5) health care professional attitudes and knowledge influence patient-centered care and perceived access to care and disease activity, and (6) health system characteristics influence patient-centered care and associated costs, perceived access to care, and disease activity.

Meaning Barriers to care associated with employment, health insurance, health care professional attributes, and health system characteristics may act synergistically to limit health care access and influence disease activity among people with hidradenitis suppurativa.

sician or confirmation in response to the following validated screening question: "Do you experience boils in your armpits or groin that recur at least every six months?"¹⁷ Final sample size was determined by thematic saturation.

Data Analysis

All interview transcripts were imported into Dedoose, an online mixed-method data-analysis program.¹⁸ We used a grounded theory approach to develop a codebook, wherein investigators used the transcripts to generate themes (N.S., M.P., M.C.H., H.B.N.). Three investigators (including N.S. and M.P.)

Table 1. Demographic Characteristics of the Study Participants (N = 45)

| Characteristic | No. (%) |
|-----------------------------|---------|
| Age, median (IQR), y | 37 (16) |
| Gender | |
| Female | 33 (73) |
| Male | 12 (27) |
| Race and ethnicity | |
| African American | 11 (24) |
| Asian | 5 (11) |
| Hispanic | 6 (13) |
| White | 22 (49) |
| Other ^a | 1 (2) |
| Annual household income, \$ | |
| <25 000 | 5 (11) |
| 25 000-49 000 | 5 (11) |
| 50 000-74 000 | 13 (29) |
| 75 000-99 000 | 3 (7) |
| 100 000-124 000 | 6 (13) |
| 125 000-149 000 | 4 (9) |
| 150 000-174 000 | 2 (4) |
| >175 000 | 6 (13) |
| Abstained | 1 (2) |

^a Other is reported both to deidentify and not add additional interpretation to this single participant's race and ethnicity category.

Table 2. Main Themes and Dimensions^a

| Theme | Dimensions |
|---------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Theme 1: Bidirectional associations of disease activity and employment | Dimension 1: Missed work for appointments and flares Dimension 2: Influence on type of job Dimension 3: Disability benefits |
| Theme 2: Association of employment with health care coverage | Dimension 1: Health insurance is tied to employment |
| Theme 3: Association of health care coverage with costs and perceived access to care | Dimension 1: Different insurance models influence perceived access to care Dimension 2: Health insurance influences out-of-pocket costs |
| Theme 4: Association of costs with access to patient-centered care | Dimension 1: Time burden required to access care Dimension 2: Financial burden of accessing care |
| Theme 5: Health care professional attitudes and knowledge influence patient-centered care and perceived access to care and disease activity | Dimension 1: Nonverbal cues Dimension 2: Stigma and shame burden experienced in health care interactions Dimension 3: Empathy and caring Dimension 4: Respect Dimension 5: Clear and honest communication Dimension 6: Knowledgeable (dermatologists) Dimension 7: Knowledgeable (nondermatologists) |
| Theme 6: Health system characteristics influence patient-centered care and associated costs, perceived access to care, and disease activity | Dimension 1: Ability to choose from a variety of health care professionals Dimension 2: Timely care for acute disease flares Dimension 3: Care team is responsive Dimension 4: Geographic distribution of specialists Dimension 5: Multidisciplinary care approach Dimension 6: Clear communication among health care professionals Dimension 7: Continuity of care |

^a Themes match associations depicted in the proposed model in the Figure.

read the data in their entirety. We then used an inductive approach focused on identifying unifying and contrasting ideas together with a priori categories reflecting study goals to develop a draft codebook (11 parent codes and 16 child codes).¹⁹ Discrepancies were discussed and resolved through consensus. We then conducted multiple rounds of codebook revision and interrater reliability testing until all coders achieved a minimum pooled κ value greater than 0.8, indicating excellent reliability.^{20,21} The analytic team applied the full codebook to all transcribed interviews.

Three investigators (L.A.B., N.S., H.B.N.) performed a thematic analysis of all excerpts (n = 2566, with some overlapping excerpts) associated with the following codes/subcodes: (1) health systems interactions, (2) facilitators to care, (3) barriers to care, (4) income and profession, and (5) interpersonal interactions with health care. The resultant themes, sub-themes, and thematic framework were discussed and refined (L.A.B. and H.B.N.), then critiqued by 3 experienced qualitative investigators (M.C.H., I.d.V.H., E.L.) to expand understanding of the data and ensure qualitative rigor. Data saturation of the themes was achieved as demonstrated by the increasing overlap of issues raised by participants.

Results

Sociodemographic Characteristics

The characteristics of the included participants reflected diversity observed in the general US HS population. A total of 45 participants with HS from diverse demographic and socio-

economic backgrounds were interviewed (Table 1). The median (IQR) age of participants was 37 (16) years, and 11 participants (24%) identified as African American, 5 (11%) as Asian, 6 (13%) as Hispanic, and 22 (49%) as White. Consistent with the demographic characteristics of the US HS population, most participants were female (n = 33 [73%]).

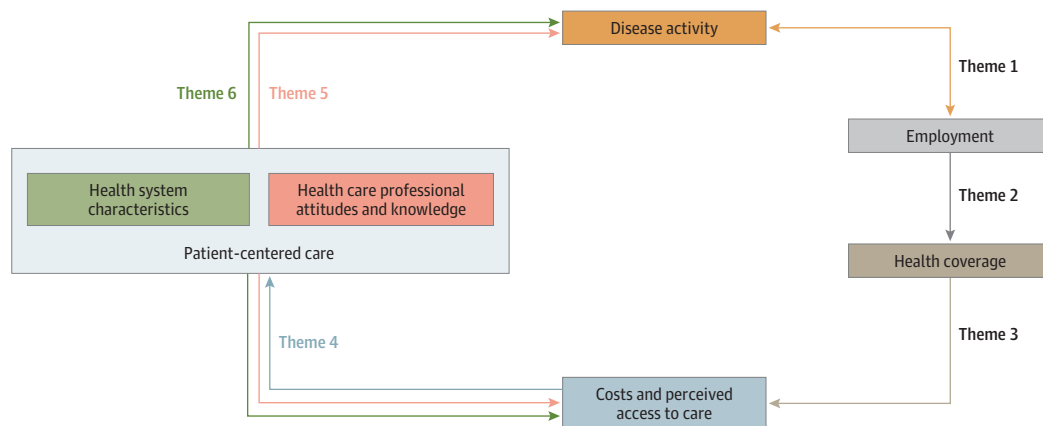
Thematic Analysis: Cyclical Barriers to Health Care Access Influence Disease Activity

Six interrelated themes (Table 2) associated with participant-perceived barriers and facilitators to care are summarized in the proposed conceptual model (Figure). This model depicts how compounding barriers may restrict access to patient-centered HS care and how reducing these barriers may improve HS disease activity and outcomes. In some situations, the themes highlight associations that are bidirectional, meaning that the association functions in 2 directions (eg, disease activity may influence an individual's ability to successfully obtain and maintain employment, but employment-related activities, such as sitting or physical activity, may also influence disease activity). Using these data, *patient-centered care* was defined as the individual's specific health needs and desired health outcomes to drive health care decisions and quality measurements.²² Representative quotations illustrating each theme can be found in the eTable in Supplement 1.

Theme 1: Bidirectional Associations of Disease Activity and Employment

The first theme refers to the bidirectional association between disease activity and employment. First, participants

Figure. Proposed Conceptual Model of Perceived Barriers and Facilitators to Care Among Participants With Hidradenitis Suppurativa



The proposed model components match their respective themes in Table 2. The arrows indicate the directionality of the association. The following themes are depicted: (1) bidirectional associations of disease activity and employment, (2) association of employment with health care coverage, (3) association of health care coverage with costs and perceived access to care, (4) association of

costs with access to patient-centered care, (5) health care professional attitudes and knowledge influence patient-centered care and perceived access to care and disease activity, and (6) health system characteristics influence patient-centered care and associated costs, perceived access to care, and disease activity.

reported that the pain, discharge, and odor associated with their HS, as well as the need to attend physician appointments for HS flares, could cause them to be absent from work or school. Second, participants also reported that HS activity influenced their career choices. For example, some people selected positions that would allow them to avoid long-term sitting, frequent walking, or in-person attendance. Third, HS severity and activity resulted in an inability to work and led some participants to file for disability benefits. Conversely, some participants reported that maintaining employment related to their skills made it difficult to control disease activity, thus suggesting bidirectionality of this theme.

Theme 2: Association of Employment With Health Care Coverage

The second theme focuses on the association participants drew between employment choices and health insurance coverage. Participants reported selecting and maintaining employment positions to access specific health insurance coverage—and even specific health care professionals—necessary for their HS care.

Theme 3: Association of Health Care Coverage With Costs and Perceived Access to Care

The third theme refers to the associations of health insurance coverage with costs and perceived access to care. First, participants emphasized how specific insurance models—including health maintenance organizations, preferred provider organizations, Medicaid/Medicare, and no insurance—influenced their ability to access HS specialists and medications. Second, participants described how health insurance influenced out-of-pocket costs. Co-payments and deductibles, in particular, were cited as prohibitive insurance-related costs, with 1 participant stating that a copay can “literally be the choice of me going to the doctor or me buying

groceries” (eTable in Supplement 1). Participants reported that insurance rarely, if ever, covered wound care supplies and bandages.

Theme 4: Association of Costs With Access to Patient-Centered Care

The fourth theme refers to costs that may affect access to patient-centered care. Participants identified 2 costs that influenced their access to patient-centered HS care, which included (1) time required to access care and (2) financial burden of accessing care. Time-related burdens included the time required to coordinate care and travel time to care. Financial costs included medical visit payments, travel costs, medications, and wound care supplies. The cumulative financial burden could be overwhelming, causing some to forgo specific therapies or services altogether. Ultimately, these out-of-pocket costs could affect other household costs and essential needs. When insurmountable, these burdens prevented participants from accessing patient-centered care.

Theme 5: Health Care Professional Attitudes and Knowledge Influence Patient-Centered Care and Perceived Access to Care and Disease Activity

The fifth theme refers to characteristics of patient-centered care that are associated with health care professional attitudes and knowledge and their potential effects on perceived access to care and disease activity. These characteristics included 7 dimensions.

First, participants commented on nonverbal cues as a factor in their comfort level with health care professionals. Second, participants described the emotional burden of perceived stigma and shame during health care interactions. Third, empathy and caring were highlighted as positive attitudes. Fourth, participants emphasized the desire to be treated with respect during visits. Fifth, clear communication was under-

scored, even if it meant the health care professional acknowledged a gap in their knowledge. In the sixth and seventh dimensions, participants highlighted the need for health care professionals knowledgeable about HS within and outside of dermatology, respectively. Taken together, these 7 dimensions illustrate health care professional characteristics that influence patient–health care professional rapport, and resultant, could influence participants’ willingness to access care (eg, perceived access to care) and management of disease activity.

Theme 6: Health System Characteristics Influence Patient-Centered Care and Associated Costs, Perceived Access to Care, and Disease Activity

In the sixth theme, participants noted 7 distinct dimensions of health systems that facilitate patient-centered care and improve health care costs, perceived access to care, and disease activity. First, the ability to select or change health care professionals was noted to influence perceived access to care. Second, the lack of dermatology appointment availability for acute HS flares often led to presenting to acute care facilities and influenced disease activity. Some participants also commended their care teams for having the infrastructure to address acute flares. Third, participants noted that a responsive care team helped triage issues that could be managed at home vs issues requiring a health care appointment. Fourth, the geographic distribution of specialists limited access to patient-centered HS care and may have contributed to lack of timely management of HS activity. Fifth, a multidisciplinary approach (including obstetrics/gynecology, primary care, mental health, wound care, and pain management) was emphasized for patient-centered HS care and was felt to have benefits for both perceived access to care and, ultimately, disease activity. Sixth, systems for clear communication among care team members were noted to facilitate cohesive care and optimize HS management. Seventh, the importance of care continuity for a chronic disease like HS was highlighted, which facilitated cohesive and seamless care to improve disease activity without the need to repeat previously failed treatment modalities for documentation purposes.

Discussion

In this study, in-depth semistructured interviews with a demographically and socioeconomically diverse group of people with HS informed the development of a model depicting a cyclical association of barriers and facilitators that may influence the ability of people with HS to access patient-centered care for their disease. We highlighted 6 themes in this model and indicated potential association directionality with arrows (Figure).

The present data support a bidirectional association between HS disease activity and employment. Most participants described the influence of their HS disease activity on employment, which could prevent them from working altogether. This is consistent with previously published work on the association of HS disease activity with school and

work.^{5,13,23–35} The majority of people with HS (as high as 58%) are likely to miss work and school.^{23,25,30,34} When at work, they also more likely to have a 20% to 30% reduction in productivity due to disease activity.^{32,34} In one study, work and activity impairment increased with increasing Hurley stage,³² emphasizing the progressive influence of HS disease activity on work. In addition, people with HS have been previously shown to have higher total days of work loss (18.4 vs 7.7) and increased risk of leaving the work force (adjusted hazard ratio, 1.65) when compared with controls.³⁰ Notably, however, participants also highlighted the influence of employment-related activities on disease activity, which to our knowledge has not previously been reported in the literature, citing instances where long-term sitting or physical activity required for their job could worsen their HS disease activity. In addition to emphasizing the associations between disease activity and employment, the present model supports the more substantial and potentially compounding influence of disease activity on one’s ability to access patient-centered care.

The model also depicts a directional association between employment and health care coverage, as participants highlighted that their employers provided health care coverage. Many participants reported their dependence on employer-provided health care coverage to cover their high medical expenses, which ultimately prevented them from changing or leaving their jobs, a phenomenon known as *job lock*³⁶ that has been well described in the context of chronic illnesses and cancer.^{37–39} Interestingly, job lock is more common in women and those with chronic illnesses.^{37,39} Given the female predominance observed in HS, people with HS may be at higher risk of job lock even compared with those with other chronic illnesses. A novel contribution of this study is the reporting of this phenomenon in people with HS. Further in-depth analysis is warranted to understand the emotional and financial implications of job lock in this patient population.

The present data support the directional influence that different types of health care coverage can have on health care-related costs and perceived access to care, emphasizing the perceptions of the cost associated with varying insurance models and out-of-pocket costs. While a single study has used claims data to compare health care costs between patients with HS and Medicaid to those with commercial/Medicare insurance,⁴⁰ a novel contribution of this study is the unique examination of patient-perceived differences in financial costs for HS care across insurance plans. This report adds to the growing body of literature examining the real-life burdens of out-of-pocket health care costs for people with inflammatory skin diseases, including atopic dermatitis⁴¹ and alopecia areata.⁴²

The present model highlights how costs can influence access to patient-centered care and how the quality of patient-centered care can influence costs and perceived care access. The data indicate 2 key dimensions of costs, including financial costs and time-related costs associated with accessing health care services. A similar concept (“cost of illness”) highlights the increased direct medical (physician consultations, inpatient admissions, and surgeries), direct nonmedical (transportation and caregiving), and indirect costs (productivity loss) for people with HS.⁴³ In addition, people with HS expend con-

siderable time seeking care, as evidenced by higher rates of emergency department utilization and hospitalization when compared with those with psoriasis, another chronic inflammatory condition, and controls.²⁵ A novel contribution of the present work is that it adds the specific lived experiences of people with HS while navigating direct and indirect costs of their care.

The interviews also uncovered 2 key dimensions of patient-centered care: (1) health care professional attitudes and knowledge and (2) health system characteristics. Given the widely recognized historical neglect of people with HS within the medical field and the long-standing lack of approved and effective treatments for this condition,^{44,45} optimizing health care professional attitudes and knowledge about HS are key to providing patient-centered care. In line with previous reports,^{13,25,46} participants in this study emphasized using emergency departments and inpatient care to address acute flares due to difficulties accessing timely and affordable outpatient services. The recurrent and extremely painful nature of HS,⁴⁷⁻⁵¹ as well as the numerous associated comorbidities,³ require adjustments of health care system characteristics to accommodate timely care for acute flares and to ensure coordinated multidisciplinary care to improve access to patient-centered care and, subsequently, reduce overall disease burden. A similar emphasis on the need for health care professionals (specifically consulting physicians) to develop trustful relationships with a humanistic approach, the need for timely care for flares, and the need for multidisciplinary care including psychosocial care has been described in a qualitative study of people with atopic dermatitis.⁵² The present work, however, adds novel granularity describing ways that health care professional attitudes and knowledge and health system characteristics can be optimized. While implementing individual- and system-level changes to improve access to patient-centered care may be challenging, findings from this study suggest that there may be several specific actions health care professionals and systems can take to improve the perceived quality of care. This includes maintaining a humanistic approach with patients with an emphasis on verbal and nonverbal communication, enhancing knowledge about HS diagnosis and treatment, and providing additional options for acute HS flare management,^{13,22,53-55} as was recommended in a recent qualitative metasynthesis study.⁵⁶ The cyclical model rooted in rich data highlights how various factors, including health care systems, employment, logistics related to health care coverage options, and interpersonal relationships within the health care system, may influence the ability of people with HS to access patient-centered care for their condition. However, associations that were not described in the data may also

exist among contiguous and noncontiguous elements of the cycle. For example, acute disease-related flares may directly increase financial costs via co-payment for a clinic visit and administration of intralesional steroids without affecting employment or health coverage beforehand.

In addition, the proposed model may also be relevant for other dermatologic conditions with similar substantial burdens on physical function, self-image, and access to care, such as atopic dermatitis.⁵⁷ However, unlike other visible dermatologic conditions with waxing and waning courses, HS is unique in its associated debilitating pain,⁴⁷⁻⁵¹ progression to irreversible scarring,⁹ absence of uniformly effective therapies,⁴⁴ and a decades-long history of neglect by the medical community.^{58,59} The present model suggests that timely intervention in this cycle may be key to optimizing patient-centered HS care.

Strengths and Limitations

Key strengths of this study include the large size, demographic and socioeconomic diversity of the rich data set, and rigorous data collection and thematic analysis methodology. Importantly, we recruited geographically and socioeconomically diverse US participants, underscoring the diversity of the cohort and generalizability of the data. However, this study has some limitations. Because we focused on the perspectives of adults with HS, the perspectives of pediatric participants with HS are not reflected. Clinical data on disease severity were not collected, so we cannot quantitatively assess associations between clinical disease severity and the identified themes. Additionally, HS is associated with numerous comorbidities³; however, examining the role of comorbid diseases in access to patient-centered care was beyond the scope of this study. Despite the study participants' broad demographic and socioeconomic diversity, there may be associations that are not depicted in the data and model. However, given the cohort's size and diversity, it is unlikely that we failed to uncover common themes.

Conclusions

This hypothesis-generating qualitative study proposes a cyclical conceptual model with 6 key themes to understand the associations between barriers and facilitators to HS care and provides insights for health care professionals and health care systems caring for this patient population. Further studies are needed to confirm these hypothesized associations in larger samples of people with HS across health care systems and to test interventions to improve access to clinical care for people with HS.

ARTICLE INFORMATION

Accepted for Publication: February 9, 2023.

Published Online: April 5, 2023.

doi:10.1001/jamadermatol.2023.0486

Author Contributions: Dr Naik had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Concept and design: Barnes, Shukla, Halley, Linos, Naik.

Acquisition, analysis, or interpretation of data:

All authors.

Drafting of the manuscript: Barnes, Shukla, Naik.

Critical revision of the manuscript for important intellectual content: All authors.

Statistical analysis: Linos.

Obtained funding: Linos.

Administrative, technical, or material support:

Barnes, Shukla, Paul, de Vere Hunt, Linos, Naik.

Supervision: Linos, Naik.

Conflict of Interest Disclosures: Dr Naik reported grants from AbbVie; personal fees from 23andMe, AbbVie, Aristea Therapeutics, Nimbus Therapeutics, Medscape, DAVA Oncology, Sonoma Biotherapeutics, Boehringer Ingelheim, Novartis, Pfizer, Radera, and UCB (Union Chimique Belge).

all outside the submitted work; shares of Radera; and serves as a board member of the Hidradenitis Suppurativa Foundation. No other disclosures were reported.

Funding/Support: This study was funded through grants from the National Institute of Arthritis and Musculoskeletal and Skin Diseases (K23 AR074531 and K24 AR075060).

Role of the Funder/Sponsor: The National Institute of Arthritis and Musculoskeletal and Skin Diseases had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

Disclaimer: Dr Naik is an Associate Editor of *JAMA Dermatology* but was not involved in any of the decisions regarding review of the manuscript or its acceptance.

Data Sharing Statement: See [Supplement 2](#).

Additional Contributions: We thank Fatuma Rinderknecht, BA, of the School of Medicine, University of California, San Francisco, for her assistance with coding. She was not compensated for her contributions. We also thank Hannah Balter, BS, of the Department of Dermatology, University of California, San Francisco, for her assistance with figure design. She was not compensated beyond her salary.

REFERENCES

1. Alikhan A, Lynch PJ, Eisen DB. Hidradenitis suppurativa: a comprehensive review. *J Am Acad Dermatol*. 2009;60(4):539-561. doi:10.1016/j.jaad.2008.11.911
2. Buimer MG, Wobbes T, Klinkenbijl JH. Hidradenitis suppurativa. *Br J Surg*. 2009;96(4):350-360. doi:10.1002/bjs.6569
3. Garg A, Malviya N, Strunk A, et al. Comorbidity screening in hidradenitis suppurativa: evidence-based recommendations from the US and Canadian Hidradenitis Suppurativa Foundations. *J Am Acad Dermatol*. 2022;86(5):1092-1101. doi:10.1016/j.jaad.2021.01.059
4. Nguyen TV, Damiani G, Orenstein LAV, Hamzavi I, Jemec GB. Hidradenitis suppurativa: an update on epidemiology, phenotypes, diagnosis, pathogenesis, comorbidities and quality of life. *J Eur Acad Dermatol Venereol*. 2021;35(1):50-61. doi:10.1111/jdv.16677
5. Kirby JS, Thorlacius L, Villumsen B, et al. The Hidradenitis Suppurativa Quality of Life (HiSQOL) score: development and validation of a measure for clinical trials. *Br J Dermatol*. 2020;183(2):340-348. doi:10.1111/bjd.18692
6. Bouazzi D, McPhie ML, Kjaersgaard Andersen R, Alavi A, Jemec GBE. Hidradenitis suppurativa and perceived stigmatization in a diverse Canadian clinic population: a pilot study. *Br J Dermatol*. 2021;184(3):570-571. doi:10.1111/bjd.19626
7. Montero-Vilchez T, Diaz-Calvillo P, Rodriguez-Pozo JA, et al. The burden of hidradenitis suppurativa signs and symptoms in quality of life: systematic review and meta-analysis. *Int J Environ Res Public Health*. 2021;18(13):6709. doi:10.3390/ijerph18136709
8. Saunte DM, Boer J, Stratigos A, et al. Diagnostic delay in hidradenitis suppurativa is a global problem. *Br J Dermatol*. 2015;173(6):1546-1549. doi:10.1111/bjd.14038
9. Saunte DML, Jemec GBE. Hidradenitis suppurativa: advances in diagnosis and treatment. *JAMA*. 2017;318(20):2019-2032. doi:10.1001/jama.2017.16691
10. Orenstein LAV, Nguyen TV, Damiani G, Sayed C, Jemec GBE, Hamzavi I. Medical and surgical management of hidradenitis suppurativa: a review of international treatment guidelines and implementation in general dermatology practice. *Dermatology*. 2020;236(5):393-412. doi:10.1159/000507323
11. Bertolotti A, Sbidian E, Join-Lambert O, et al; HS working group; Centre of Evidence of the French Society of Dermatology. Guidelines for the management of hidradenitis suppurativa: recommendations supported by the Centre of Evidence of the French Society of Dermatology. *Br J Dermatol*. 2021;184(5):963-965. doi:10.1111/bjd.19710
12. Giuffrida R, Cannavò SP, Coppola M, Guarneri C. Novel therapeutic approaches and targets for the treatment of hidradenitis suppurativa. *Curr Pharm Biotechnol*. 2021;22(1):59-72. doi:10.2174/1389201021666200505100556
13. 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(6):1490-1492. doi:10.1111/bjd.18818
14. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357. doi:10.1093/intqhc/mzm042
15. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89(9):1245-1251. doi:10.1097/ACM.0000000000000388
16. Miller EG, Woodward AL, Flinchum G, Young JL, Tabor HK, Halley MC. Opportunities and pitfalls of social media research in rare genetic diseases: a systematic review. *Genet Med*. 2021;23(12):2250-2259. doi:10.1038/s41436-021-01273-z
17. Esmann S, Dufour DN, Jemec GB. Questionnaire-based diagnosis of hidradenitis suppurativa: specificity, sensitivity and positive predictive value of specific diagnostic questions. *Br J Dermatol*. 2010;163(1):102-106. doi:10.1111/j.1365-2133.2010.09773.x
18. Dedoose, version 9.0.17. Accessed February 22, 2023. <http://www.dedoose.com>
19. Halley MC, Rustagi AS, Torres JS, et al. Physician mothers' experience of workplace discrimination: a qualitative analysis. *BMJ*. 2018;363:k4926. doi:10.1136/bmj.k4926
20. Cohen J. A coefficient of agreement for nominal scales. *Educ Psychol Meas*. 1960;20(1):37-46. doi:10.1177/001316446002000104
21. De Vries H, Elliott MN, Kanouse DE, Tekki SS. Using pooled kappa to summarize interrater agreement across many items. *Field Methods*. 2008;20(3):272-282. doi:10.1177/1525822X08317166
22. Constand MK, MacDermid JC, Dal Bello-Haas V, Law M. Scoping review of patient-centered care approaches in healthcare. *BMC Health Serv Res*. 2014;14:271. doi:10.1186/1472-6963-14-271
23. Matusiak Ł, Bieniek A, Szepletowski JC. Hidradenitis suppurativa markedly decreases quality of life and professional activity. *J Am Acad Dermatol*. 2010;62(4):706-708, 708.e1. doi:10.1016/j.jaad.2009.09.021
24. Esmann S, Jemec GB. Psychosocial impact of hidradenitis suppurativa: a qualitative study. *Acta Derm Venereol*. 2011;91(3):328-332. doi:10.2340/00015555-1082
25. Kirby JS, Miller JJ, Adams DR, Leslie D. Health care utilization patterns and costs for patients with hidradenitis suppurativa. *JAMA Dermatol*. 2014;150(9):937-944. doi:10.1001/jamadermatol.2014.691
26. Sisic M, Kirby JS, Boyal S, Plant L, McLellan C, Tan J. Development of a quality-of-life measure for hidradenitis suppurativa. *J Cutan Med Surg*. 2017;21(2):152-155. doi:10.1177/1203475416677721
27. Kimball AB, Sundaram M, Banderas B, Foley C, Shields AL. Development and initial psychometric evaluation of patient-reported outcome questionnaires to evaluate the symptoms and impact of hidradenitis suppurativa. *J Dermatolog Treat*. 2018;29(2):152-164. doi:10.1080/09546634.2017.1341614
28. Thorlacius L, Ingram JR, Villumsen B, et al; Hidradenitis Suppurativa CoRE outcomes set International Collaboration (HISTORIC). A core domain set for hidradenitis suppurativa trial outcomes: an international Delphi process. *Br J Dermatol*. 2018;179(3):642-650. doi:10.1111/bjd.16672
29. Thorlacius L, Esmann S, Miller I, Vinding G, Jemec GBE. Development of HiSQOL: a hidradenitis suppurativa-specific quality of life instrument. *Skin Appendage Disord*. 2019;5(4):221-229. doi:10.1159/000496234
30. Tzellos T, Yang H, Mu F, Calimlim B, Signorovitch J. Impact of hidradenitis suppurativa on work loss, indirect costs and income. *Br J Dermatol*. 2019;181(1):147-154. doi:10.1111/bjd.17101
31. Patel ZS, Hoffman LK, Sutton L, Cohen SR, Lowes MA, Seng EK. The patient experience of pain in hidradenitis suppurativa. *Br J Dermatol*. 2020;183(2):401-402. doi:10.1111/bjd.19016
32. Sandhu VK, Shah M, Piguet V, Alavi A. The impact of hidradenitis suppurativa on work productivity and activity impairment. *Br J Dermatol*. 2020;182(5):1288-1290. doi:10.1111/bjd.18695
33. Sarfo A, Butt M, Kirby JS. Periodic worsening, or flare, in hidradenitis suppurativa: the perspective of people with hidradenitis. *Br J Dermatol*. 2020;182(1):218-219.
34. Yao Y, Jørgensen AR, Thomsen SF. Work productivity and activity impairment in patients with hidradenitis suppurativa: a cross-sectional study. *Int J Dermatol*. 2020;59(3):333-340. doi:10.1111/ijd.14706
35. Theut Riis P, Thorlacius L, Knudsen List E, Jemec GBE. A pilot study of unemployment in patients with hidradenitis suppurativa in Denmark. *Br J Dermatol*. 2017;176(4):1083-1085. doi:10.1111/bjd.14922
36. Rashad I, Sarpong E. Employer-provided health insurance and the incidence of job lock: a literature review and empirical test. *Expert Rev Pharmacoecon Outcomes Res*. 2008;8(6):583-591. doi:10.1586/14737167.8.6.583
37. Stroupe KT, Kinney ED, Kniesner JJ. Chronic illness and health insurance-related job lock.

J Policy Anal Manage. 2001;20(3):525-544. doi:10.1002/pam.1006

38. Kent EE, de Moor JS, Zhao J, Ekwueme DU, Han X, Yabroff KR. Staying at one's job to maintain employer-based health insurance among cancer survivors and their spouses/partners. *JAMA Oncol.* 2020;6(6):929-932. doi:10.1001/jamaoncol.2020.0742

39. Huysse-Gaytandjieva A, Groot W, Pavlova M. A new perspective on job lock. *Soc Indic Res.* 2013; 112(3):587-610. doi:10.1007/s11205-012-0072-2

40. Marvel J, Vlahiotis A, Sainski-Nguyen A, Willson T, Kimball A. Disease burden and cost of hidradenitis suppurativa: a retrospective examination of US administrative claims data. *BMJ Open.* 2019;9(9):e030579. doi:10.1136/bmjopen-2019-030579

41. Chovatiya R, Begolka WS, Thibau JJ, Silverberg JI. Financial burden and impact of atopic dermatitis out-of-pocket healthcare expenses among black individuals in the United States. *Arch Dermatol Res.* 2022;314(8):739-747. doi:10.1007/s00403-021-02282-3

42. Li SJ, Mostaghimi A, Tkachenko E, Huang KP. Association of out-of-pocket health care costs and financial burden for patients with alopecia areata. *JAMA Dermatol.* 2019;155(4):493-494. doi:10.1001/jamadermatol.2018.5218

43. Gáspár K, Hunor Gergely L, Jenei B, et al. Resource utilization, work productivity and costs in patients with hidradenitis suppurativa: a cost-of-illness study. *Expert Rev Pharmacoecon Outcomes Res.* 2022;22(3):399-408. doi:10.1080/14737167.2021.1895753

44. 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(1):91-101. doi:10.1016/j.jaad.2019.02.068

45. AbbVie's HUMIRA® (adalimumab) receives first and only US Food and Drug Administration approval for moderate to severe hidradenitis suppurativa. News release. AbbVie. September 10, 2015. Accessed February 22, 2023. <https://news.abbvie.com/news/abbvies-humira-adalimumab-receives-first-and-only-us-food-and-drug-administration-approval-for-moderate-to-severe-hidradenitis-suppurativa.htm>

46. Khalsa A, Liu G, Kirby JS. Increased utilization of emergency department and inpatient care by patients with hidradenitis suppurativa. *J Am Acad Dermatol.* 2015;73(4):609-614. doi:10.1016/j.jaad.2015.06.053

47. Taylor MT, Orenstein LAV, Barbieri JS. Pain severity and management of hidradenitis suppurativa at US emergency department visits. *JAMA Dermatol.* 2021;157(1):115-117. doi:10.1001/jamadermatol.2020.4494

48. Savage KT, Singh V, Patel ZS, et al. Pain management in hidradenitis suppurativa and a proposed treatment algorithm. *J Am Acad Dermatol.* 2021;85(1):187-199. doi:10.1016/j.jaad.2020.09.039

49. Jedrzejczak MJ, Ingram JR, Lowes MA, et al. Expert knowledge, attitudes, and practices in management of hidradenitis suppurativa pain. *JAMA Dermatol.* 2021;157(4):464-466. doi:10.1001/jamadermatol.2020.5857

50. Hasan SB, Gendra R, James J, Morris D, Orenstein LAV, Ingram JR. Pain measurement in painful skin conditions and rheumatoid arthritis randomized controlled trials: a scoping review to inform pain measurement in hidradenitis suppurativa. *Br J Dermatol.* 2022;187(6):846-854. doi:10.1111/bjd.21821

51. Fernandez JM, Thompson AM, Borgstrom M, Orenstein LAV, Hsiao JL, Shi VY. Pain management modalities for hidradenitis suppurativa: a patient survey. *J Dermatolog Treat.* 2022;33(3):1742-1745. doi:10.1080/09546634.2020.1822501

52. de Wijs LEM, van Egmond S, Devillers ACA, Nijsten T, Hijnen D, Lugtenberg M. Needs and

preferences of patients regarding atopic dermatitis care in the era of new therapeutic options: a qualitative study. *Arch Dermatol Res.* 2023;315(1): 75-83. doi:10.1007/s00403-021-02321-z

53. Willems D, Hilgsmann M, van der Zee HH, Sayed CJ, Evers SMAA. Identifying unmet care needs and important treatment attributes in the management of hidradenitis suppurativa: a qualitative interview study. *Patient.* 2022;15(2): 207-218. doi:10.1007/s40271-021-00539-7

54. 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(2):366-376. doi:10.1016/j.jaad.2019.06.1301

55. Bettoli V, Pasquinucci S, Caracciolo S, et al. The Hidradenitis suppurativa patient journey in Italy: current status, unmet needs and opportunities. *J Eur Acad Dermatol Venereol.* 2016;30(11):1965-1970. doi:10.1111/jdv.13687

56. Howells L, Lancaster N, McPhee M, et al. Thematic synthesis of the experiences of people with hidradenitis suppurativa: a systematic review. *Br J Dermatol.* 2021;185(5):921-934. doi:10.1111/bjd.20523

57. Falissard B, Simpson EL, Guttman-Yassky E, et al. Qualitative assessment of adult patients' perception of atopic dermatitis using natural language processing analysis in a cross-sectional study. *Dermatol Ther (Heidelb).* 2020;10(2):297-305. doi:10.1007/s13555-020-00356-0

58. Sabat R, Jemec GBE, Matusiak Ł, Kimball AB, Prens E, Wolk K. Hidradenitis suppurativa. *Nat Rev Dis Primers.* 2020;6(1):18. doi:10.1038/s41572-020-0149-1

59. Naik HB, Lowes MA. A call to accelerate hidradenitis suppurativa research and improve care-moving beyond burden. *JAMA Dermatol.* 2019;155(9):1005-1006. doi:10.1001/jamadermatol.2019.1105