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## Healthcare experiences among patients with hidradenitis suppurativa: a qualitative study

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Dear Editor, Hidradenitis suppurativa (HS) is a chronic inflammatory skin disease that causes painful, malodorous abscesses, nodules and tunnels. Patients with HS often feel misunderstood, unheard and dismissed by providers, which may lead to mistrust and disengagement from healthcare services.<sup>1</sup> This qualitative study sought to elucidate how healthcare interactions affect people living with HS.

English-speaking adults with dermatologist-diagnosed HS and a 1-week numeric rating scale pain score  $\geq 1$  were eligible. Semi-structured interviews were conducted among 21 patients (76% female, 71% Black, 96% Hurley stage II/III). Interview questions explored experience of pain, pain management, medical decision-making and attitudes towards health care. This report focused on thematic analysis of healthcare experiences and attitudes, with representative quotations provided in Table 1. Full study methods and results related to pain experience and management in HS have been reported previously.<sup>2</sup>

Participants described negative experiences of misdiagnosis and mismanagement, which they believed stemmed from insufficient provider knowledge about HS. Initial misdiagnosis delayed receipt of appropriate care. One participant received 13 surgeries over 8 years, which she attributed to providers' poor knowledge of medical therapies. Misdiagnosis also exacerbated feelings of stress and isolation.

Conversely, participants trusted providers with more HS-specific knowledge and often felt that dermatologists were best suited to manage HS. Even among dermatologists, some participants preferred HS subspecialists, who they perceived as knowledgeable about emerging therapies and passionate about HS. One participant reported that prior dermatologists would 'run out of answers', resulting in her referral to a dermatologist subspecializing in HS. Given the shortage of HS specialists and perceived lack of expertise

**Table 1** Excerpts from qualitative interviews with patients with hidradenitis suppurativa (HS) describing factors that impact healthcare experiences

Theme	Participant quote
Misdiagnosis	'From 17 until 30 years old, I was living with HS undiagnosed. Didn't know that I had HS. And my primary care doctor then was, I guess, a doctor that didn't know a lot about HS...it just kept getting misdiagnosed. Cellulitis, ingrown hair, just everything else but HS. At 30 years old, I got pregnant with twins. And when I went to my OB-GYN doctor, which was a Black lady, she knew exactly what it was. The OB-GYN doctor. She knew right off the bat exactly what it was. And that's when I was diagnosed with HS at 30 years old pregnant with twins.' (38-year-old female, Hurley stage III)
Provider knowledge	'There's a website to find providers who specialize in HS...I definitely recommend anybody who has that should do that instead of just going to any doctor, dermatologist, because even if they know what it is, that doesn't mean that they know how to treat it to any extent. That is the most important part of the disease, I think, is finding somebody who's willing to work with you, somebody who's educated and somebody who's willing to think outside of the box because HS is such a case-by-case thing.' (20-year-old female, Hurley stage III)
Racial concordance with providers	'I feel like they [Black doctors] understand more and they know more...These spots are on my leg. I know African American doctors that tell me that they know what they can get that can clear this up [vs.] Caucasian doctors...' (28-year-old female, Hurley stage III)
Gender concordance with providers	'I do have a significant preference for being seen by other women because I have felt much more dismissed by male providers in the past. And I felt that, especially things like pain; pain is actually a really good example of things that just get dismissed a lot more easily in general. So I usually only see female providers because of that.' (34-year-old female, Hurley stage II)
Pain minimization and stigma	'A part of me says you should go in there and beat around the bush and pretend like, "oh, you should suggest that I need pain medicine"; so that I don't seem like I'm a drug addict. But why should I as a patient be subject to your preconceived notions [pounds the table] of me?' (25-year-old female, Hurley stage II)
Access to care	'The alternatives are urgent-care clinics and ERs and at ERs it costs \$350 that you don't have just laying around because ya know, glorious healthcare system and urgent care clinics would rather just send you home in obvious writhing pain, than give you pills because it's so taboo and obviously you're addicted to them.' (25-year-old female, Hurley stage II)
Care coordination	'And then working together as a team between primary care and dermatology and whomever else, that would make sense. Even you know, [a] psychologist, just all working together with the whole mental health aspect of HS, and just trying to combat it from different angles, instead of just one straightforward way, would be probably helpful for a lot of people.' (40-year-old female, Hurley stage III)
Patient-centred care	'But I think listening is really just the biggest thing; even if you can't do what I'm asking you to do, it makes the biggest difference to someone who will just listen and at least be open to the idea. I do understand malpractice is a thing, but at least hear me out, because when you feel hopeless it makes the biggest difference somebody just listening to you.' (20-year-old female, Hurley stage III)

ER, emergency room; OB-GYN, obstetrician-gynaecologist.

among general dermatologists, residency programmes may consider expanding HS didactics and experiential learning.

Some Black participants valued racial concordance with providers, feeling that Black physicians were more knowledgeable about HS and more skilled in treating sequelae such as postinflammatory hyperpigmentation. One woman preferred female providers, as prior male providers had dismissed her HS pain. Given the disproportionate impact of HS on Black women,<sup>3</sup> dermatologists should consider how implicit bias may impact their care of patients with HS and adequate pain management.

Participants experienced pain minimization and stigmatization from healthcare providers, explaining that providers often focused on visible signs of HS and failed to address its psychosocial impact. Some participants reported that dermatologists did not ask about or address pain at all. In acute care settings, providers were unreceptive to prescribing opioids, and patients requesting opioids for HS pain felt that they were treated as 'drug seekers'. Owing to fear of stigmatization, some participants endured severe pain rather than requesting analgesics. In other chronic diseases with acute pain flares, such as sickle cell anaemia, evidence-based guidelines recommend developing individualized pain plans.<sup>4</sup> HS pain plans may include safe pain management at home and facilitate communication with acute care providers.

The unpredictability of painful HS flares, compounded by poor urgent access to dermatologists, was a major stressor for participants. Dermatology appointments were often unavailable during flares, leading participants to visit urgent care or emergency departments, where they experienced misdiagnosis, pain minimization, stigmatization and high cost. Further, providers in high-acuity settings often redirected responsibility for flare management to unavailable outpatient specialists, further delaying care. Approximately 80% of patients with HS flare at least monthly;<sup>5</sup> there is a need to improve timely access to dermatologists.

Patients also reported difficulty coordinating their own multidisciplinary care, reporting inadequate provider-to-provider communication, lost work time to attend multiple appointments and embarrassment in having to re-tell their stories. In other chronic diseases such as diabetes and heart failure, interdisciplinary clinics improve health outcomes and patient satisfaction.<sup>6,7</sup> Integrative care models have been proposed for improving HS management;<sup>8</sup> this study supports such a need.

Participants described more positive healthcare experiences when providers demonstrated empathy and patient-centredness through open-mindedness, active listening, consideration of patients' goals, and limiting judgement and bias. Empathic communication made patients more comfortable showing their HS lesions and discussing

their experiences. Participants valued transparency regarding realistic expectations, chances of improvement and medication effects of treatments to facilitate shared decision-making.

This study has limitations. Interviews were primarily designed to characterize HS pain experiences rather than healthcare experiences, which may have led to an overemphasis of pain. Yet, inductive analysis of these semi-structured interviews raised important themes surrounding healthcare experiences beyond the context of HS-related pain. Additionally, most participants had moderate-to-severe HS and were recruited from a specialty clinic, which could have amplified or diminished certain perspectives.

This qualitative study highlights negative healthcare experiences that may erode trust in the healthcare institution and contribute to poor patient outcomes. Additional work is needed to quantify these problems and develop interventions to improve healthcare experiences for patients with HS.

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**Data availability:** the data underlying this article will be shared upon reasonable request to the corresponding author.

**Ethics statement:** this study was reviewed and approved by Emory Institutional Review Board (approval #115645).

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