

# Communicating with health providers and romantic partners: The impact of negative emotions on quality of life for individuals with hidradenitis suppurativa

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## ABSTRACT

**Background:** Hidradenitis suppurativa (HS) is a chronic, inflammatory, debilitating skin disease that impacts an estimated 1 to 4% of the population; women are twice as likely to be diagnosed as men. There is no cure for HS, and many patients face a lifetime of various healthcare appointments, medical interventions, and personal experiences living with the disease.

**Objective:** This study aimed to explore social, emotional, and medical experiences for individuals with HS, and to understand connections between those experiences and quality of life.

**Methods:** Participants (n = 243) in the community-based convenience sample completed a cross-sectional survey about their experiences and quality of life and reported high rates of anxiety, embarrassment, and depressed mood. These and other negative emotions were commonly experienced during interactions with healthcare providers and romantic partners.

**Results:** Participants who had more negative interactions with providers and partners surrounding their HS tended to experience a lower quality of life.

**Limitations:** Limited generalizability due to convenience sampling.

**Conclusion:** Providers should consider how patients experience patient-provider communication about HS, and how this communication impacts other areas of patients' lives, including quality of life, mental health, and romantic relationships. Future care approaches should prioritize mental health strategies in HS patients' care plans, and establish partnerships between dermatology practices and mental health professionals to aid in the multidisciplinary approach recommended for the treatment of HS.

**Keywords:** hidradenitis suppurativa, patient-provider communication, quality of life

## Introduction

Hidradenitis suppurativa (HS) is a chronic, inflammatory, debilitating skin disease that often presents during or after puberty and impacts an estimated 1 to 4% of the population. It is characterized by painful, deep, and inflamed lesions mainly in the groin, perineum, genital, and underarm areas, though other areas of the body can be affected.<sup>1-3</sup> Clinicians and researchers have pinpointed many intersecting factors that may impact HS—such as genetic, endocrinological, bacterial, environmental, and lifestyle factors—but no one specific cause has been identified.<sup>4</sup> Similarly, many different treatment options exist for patients with HS, though none have been documented to work for all patients. Women are more than twice as likely to

be diagnosed with HS than men with higher prevalence among people of color.<sup>3</sup> Currently there is no cure for HS; patients can

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

- Overall, the quality of life scores of patients with Hidradenitis suppurativa (HS) is lower than patients with other chronic dermatological conditions.
- Women are twice as likely than men to be diagnosed with HS.
- The families of patients with HS may be impacted given its possible disabling condition and impacts on physical and mental health.
- Very few studies have addressed the role of patient and partner communication on patients with HS.

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

- Our majority female (95%) sample experienced negative emotions when interacting with providers around HS, which was related to lower quality of life scores.
- Women in our study also experienced negative emotions when interacting with their romantic partners that was also associated with lower quality of life scores.
- Future care approaches should prioritize mental health strategies in HS patients' care plans, and establish partnerships between dermatology practices and mental health professionals to aid in the multidisciplinary approach recommended for the treatment of HS.

only manage their symptoms through medication, surgery, and/or lifestyle changes with varied reported levels of success.<sup>4,6,7</sup> The purpose of the current study was to document social, emotional, and medical challenges faced by individuals with HS and draw connections between these challenges and their quality of life.

### HS diagnosis and care

When and where a patient first seeks care for their HS is important for short- and long-term health outcomes. Many HS patients present their first symptoms to general practitioners, who successfully diagnose the disease only 20.4% of the time.<sup>8</sup> Family physicians report low confidence in diagnosing and treating the disease, even though at least 80% received some form of HS education during their medical training.<sup>1,9</sup> Patients with a confirmed HS diagnosis are often referred to multiple healthcare providers<sup>10</sup> who typically focus on treating the physical characteristics of the disease, even though HS patients also have higher rates of mental health concerns like depression, anxiety, and suicide.<sup>11</sup>

The severity of HS is traditionally classified by Hurley stages I, II, or III, depending on the progression of the disease throughout the body.<sup>1,12</sup> Disease management is complex and often requires balancing medical and surgical options, which have varying degrees of success, and also impact associated pain, psychiatric issues, and medical comorbidities.<sup>4,13</sup> Patients with HS are often advised to undergo lifestyle changes to manage symptoms, including diet restrictions to avoid foods that will cause flares, navigating which clothing fabrics will least affect daily activities, and carefully choosing which physical activities to participate in based HS severity and presence of flares.<sup>13–15</sup> While there is recent literature on HS patient counseling and treatments, there is little research on how patient-provider interactions related to HS may also impact patient outcomes.

### HS and mental health

HS impacts several areas of patients' lives, including physical pain and discomfort, the activities they can participate in, interpersonal relationships, communication with providers, and trust in the medical system. Individuals with dermatological diseases are more at risk for developing psychiatric disorders than the general population, and those with HS may be particularly affected because of the large impact it can have on their quality of life.<sup>11</sup> HS patients report emotional distress due to body dissatisfaction, shame, and stigmatization, which can lead to depression and anxiety.<sup>16</sup> Depression, anxiety, and suicide risk are all considered to be linked to HS<sup>11</sup> and personal negative illness beliefs correlate with increased depression and anxiety.<sup>17–19</sup> Research on patient experiences of HS and mental health has yet to directly measure how mental health outcomes may be influenced by patient communication with providers or romantic partners.

### Quality of life

Quality of life is defined by an individual's perception of their position in life within the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns.<sup>20</sup> Skin diseases are ranked fourth among common causes of disability worldwide, and HS presents specific challenges to quality of life due to its impact on physical, social, emotional, and sexual health.<sup>21,22</sup> Coping with HS by avoiding social, occupational, and other activities is associated with decreased health-related quality of life and increased symptoms of depression.<sup>23</sup> Misdiagnosis of HS, delays in treatment, and miscommunication with healthcare providers can also cause impairments to HS patients' quality

of life, which impacts day-to-day activities and personal relationships.<sup>8,25</sup> Beyond general health-related quality of life, HS symptoms contribute to sexual impairment for patients, with pain and suppuration commonly reported as affecting sexual relations.<sup>20</sup> Lower quality of life is common among individuals with HS, but not inevitable. Quality of life may depend on how medical providers and individuals close to the patient respond to their HS.

### The current study

HS is a chronic dermatological disease without a cure that greatly impacts those who have it. Exclusive medical focus on symptom and disease management can result in overlooking the social, emotional, and mental health experiences for those with HS, which can impact their quality of life. The current study assessed common social, emotional, and medical experiences of individuals living with HS and how these were related to their quality of life. Guided by previous research, we expected that many individuals with HS would experience strong negative emotions such as depression, anxiety, and embarrassment. We also predicted that many individuals with HS would have negative experiences with healthcare providers and romantic partners when talking about their condition. We further hypothesized that these negative interactions would be associated with a lower quality of life.

### Materials and methods

#### Participants

Participants were recruited through a community-based, convenience sample of HS online support groups, social media, and via an Instagram account created for the study. A total of 401 individuals began the survey; 263 completed at least 80% of the survey and were included in the final analyses.

#### Measures

The impact of HS on participants' daily functioning, physical discomfort, emotional well-being, sexual functioning, and occupational functioning was measured with the Hidradenitis Suppurativa Quality of Life tool (HiSQOL<sup>26</sup>). The original HiSQOL measures quality of life over the past 7 days. We used this original version and also adapted the HiSQOL to measure quality of life over the past 30 days because we wanted to see if there were any differences in HiSQOL scores, given that HS symptoms and severity can vary widely throughout the month. Because the HiSQOL items are not all on the same scale, they were converted to *z* scores before they were aggregated for a total score. Internal consistency reliability was excellent for both the 30-day ( $\alpha = .95$ ) and 7-day ( $\alpha = .95$ ) versions. Because the 7-day version tended to show slightly stronger associations with the variables of interest in this study, those data are presented in this paper.

Participants were also asked whether or not they had encountered certain feelings and experiences when communicating with healthcare providers about their HS. These included anxiety, disgust, fear, isolation, judgment, and shame. Aggregated as a scale, these 6 items had acceptable internal consistency reliability ( $\alpha = .76$ ). The 221 participants who indicated that they had a romantic or sexual partner since being diagnosed with HS were asked whether or not they had experienced the same 6 emotions with a romantic partner. The negative partner emotion scale also had acceptable internal consistency reliability ( $\alpha = .75$ ). The participants were also asked questions about their demographic characteristics and aspects of their treatment experiences, including self-reported misdiagnoses.

**Analysis**

All analyses were conducted in (IBM) SPSS version 25. This sample contained 2.3% missing data and cases were excluded listwise when the score for an analyzed variable was missing. Scale scores were computed based on all non-missing data as long as the participant gave responses for at least 80% of the items on the scale. Multivariate analysis predicting quality of life and comfort discussing HS included Hurley Stage, race, and employment status as covariates.

**Results**

**Demographics**

The sample consisted of 263 participants with a mean age of 34.8 (standard deviation = 10.5). Participants were primarily white, employed, cisgender women from the United States in Hurley stages II and III (see Table 1 for more detailed demographic information). Controlling for Hurley stage through ANCOVA (Analysis of Covariance), both race ( $F = 5.02, p = .03$ ) and employment status ( $F = 6.31, p < .01$ ) were related to the quality of life participants had with their HS as measured by the HISQOL. Nonwhite participants tended to report that their HS had a greater negative impact on their lives than white participants. Participants who were unable to work tended to report

that their HS had a greater negative impact on their lives than participants who were homemakers, volunteers, or employed at least part-time.

**Mental health impacts**

Most participants (66.2%) reported that their HS had caused them to feel at least moderately depressed over the past 7 days with 43.7% reporting that their HS led them to feel very or extremely depressed. Most participants (64.4%) also reported that their HS had caused them to feel at least moderately anxious over the past 7 days with 44.7% reporting that their HS led them to feel very or extremely anxious. Most participants (70.0%) also reported that their HS had caused them to feel at least moderately embarrassed over the past 7 days with 51.7% reporting that their HS led them to feel very or extremely embarrassed. Although mental health conditions were not assessed systematically, 18 participants listed mental health conditions such as depression and anxiety when asked what “chronic illnesses” they have experienced.

**Patient-provider communication**

Receiving an accurate diagnosis of their HS was difficult for many participants. Most (68.0%) went at least 4 years from the onset of their HS symptoms before receiving an accurate diagnosis and 26.6% went longer than 10 years. More than half (55.1%) received a misdiagnosis before an accurate diagnosis and 19.8% received 3 or more misdiagnoses. Common misdiagnoses included ingrown hairs (34.9%), acne (25.9%), folliculitis (20.1%), and staph infections (14.7%). Delay in diagnosis was not significantly related to current quality of life ( $r = -.03, p = .58$ ) or other demographic variables. However, participants who were initially misdiagnosed reported lower quality of life due to their HS than participants who were never misdiagnosed ( $t(261) = -2.26, p = .03$ ).

Many participants also found visits with healthcare providers to be emotionally challenging. The majority (75.5%) reported experiencing at least 1 type of negative emotion when communicating with healthcare providers about their HS. These emotions included anxiety (reported by 59.1%), judgment (42.8%), shame (36.2%), disgust (30.0%), and fear (29.6%). Participants who had experienced more negative emotions when communicating with healthcare providers tended to have lower quality of life ( $r = -.29, p < .01$ ) and were less comfortable talking about their HS with providers not directly responsible for treating it ( $r = -.37, p < .01$ ). The negative emotions patients experienced with their providers were not significantly related to their age ( $r = -.07, p = .25$ ) or Hurley Stage ( $r = .12, p = .07$ ), though White individuals tended to experience more negative emotions when interacting with their providers than non-white individuals ( $t = 2.08, p = .04$ ). Negative emotions with providers were

**Table 1**  
**Demographic characteristics**

	n	%
<b>Gender</b>		
Cisgender man	8	3.1
Cisgender woman	249	95.4
Non-binary/genderqueer	2	0.8
Something else	2	0.8
<b>Race</b>		
American Indian or Alaskan Native	8	3.1
Asian	6	2.3
Black or African American	26	9.9
Latinx (Latino/Latina)	26	9.9
Native Hawaiian or Pacific Islander	3	1.1
White/Caucasian	206	78.6
Something else	10	3.8
<b>Country</b>		
Australia	5	1.9
Canada	18	6.8
Ireland	8	3.0
United Kingdom	25	9.4
United States of America	185	69.8
Other countries	24	9.0
<b>Education</b>		
Some high school	6	2.3
High school graduate or GED (General Education Development)	36	13.6
Associate's degree	20	7.6
Some college or technical school	81	30.7
Bachelor's degree	63	23.9
Post-graduate or professional degree	58	22.0
<b>Employment status</b>		
Employed full-time	152	57.6
Employed part-time	23	8.7
Unemployed	19	7.2
Retired	8	3.0
Student	18	6.8
Unable to work	28	10.6
Homemaker	14	5.3
Full-time volunteer	2	0.8
<b>Hurley stage</b>		
I	12	4.3
II	132	52.6
III	107	42.6

**Table 2**  
**Correlations between study variables and HS-related quality of life over the past 7 days and the past 30 days**

	7-day HISQOL		30-day HISQOL	
	Test statistic	p	Test statistic	p
Delay in diagnosis	$r = -.06$	.38	$r = -.08$	.20
Initial misdiagnosis	$t = -2.21$	.03	$t = -1.46$	.15
Negative emotions with providers	$r = -.28$	<.01	$r = -.27$	<.01
Negative emotions with partners	$r = -.19$	<.01	$r = -.22$	<.01
Difficulty with sexual activity				
Hurley stage	$r = .35$	<.01	$r = .27$	<.01
Genital area affected by HS	$\beta = .17$	.03	$\beta = .18$	.02

HISQOL, Hidradenitis Suppurativa Quality of Life tool; HS, hidradenitis suppurativa.

not associated with the number of treatments a person had been offered ( $r = -.04, p = .50$ ).

### Partner communication

Most participants who had had a romantic or sexual partner since being diagnosed with HS reported that they were very comfortable (37.9%) or somewhat comfortable (31.7%) talking with the partner about their HS. However, others felt somewhat uncomfortable (20.3%), very uncomfortable (7.0%), or avoided talking about their HS entirely (3.1%). Even though most participants with partners reported some level of comfort talking about their HS, it was still common for these conversations to elicit negative emotions. The majority of participants (50.2%) reported experiencing at least 1 type of negative emotion when talking with their partner about their HS. The most common negative emotion was fear (25.9%), followed by shame (25.2%), disgust (16.9%), judgment (15.8%), and isolation (13.3%). Participants who reported more negative emotions when talking with romantic partners also tended to report lower quality of life ( $r = -.20, p < .01$ ). Participants who had more negative emotions with their provider also tended to have more negative emotions with their romantic partners regarding HS ( $r = .38, p < .01$ ).

Most participants (59.5%) reported that HS had a negative impact on their physical relationship with their partner, though 6.5% indicated that HS had a positive impact on their physical relationship. Most participants (56.2%) reported that HS had a neutral impact on their emotional relationship with their partner, while 26.9% indicated a negative impact and 16.9% indicated a positive impact. Hurley stage was not significantly associated with impact on physical relationship with partner ( $r = -.09, p = .18$ ) or emotional relationship with partner ( $r = -.12, p = .10$ ). However, participants with a higher Hurley stage were more likely to report that HS made sexual activity difficult ( $r = .32, p < .01$ ). Even after accounting for Hurley stage ( $\beta = .24, p < .01$ ) and HS in other parts of the body, having HS in the genital area was associated with more difficulty with sexual activity ( $\beta$  (beta) = .18,  $p = .02$ ).

### Discussion

This study aimed to explore important social, emotional, and medical experiences for individuals with HS and to understand connections between those experiences and the individuals' quality of life. Previous research has found that marginalized populations may be more severely affected by HS.<sup>24</sup> Our study found that HS had an increased negative impact on the quality of life of nonwhite persons and those unable to work than on other individuals with the same Hurley stage. Consistent with prior findings showing elevated distress in HS patients,<sup>16</sup> our sample reported high rates of anxiety, embarrassment, and depressed mood. These and other negative emotions were commonly experienced during patient interactions with their healthcare providers and romantic partners. Other studies have shown that persons with HS are likely to encounter challenges in interacting with their healthcare providers and romantic partners.<sup>8,25</sup> Ours was the first to show that patients who experience more negative emotions during these interactions tend to have a lower quality of life.

This study emphasizes previous findings about the mental health and quality of life impacts of HS. We found evidence that HS misdiagnosis was related to lower quality of life, though we did not find other relationships between diagnosis and psychosocial measures.<sup>8,25</sup> The majority of our participants attributed moderate anxiety and depression to HS in the last 7 days and this was influenced by Hurley stage.<sup>11,16</sup> We also found that negative provider interactions were correlated with negative romantic partner emotions and lower quality of life, supporting previous research on patient-provider impacts on quality

of life.<sup>8,25</sup> Women are more than twice as likely to be diagnosed with HS than men<sup>5</sup> and 95% of our sample consisted of women, demonstrating the importance of the disease's impact on women's quality of life.

The generalizability of these findings is limited due to community-based convenience sampling and sample demographics, including limited racial and gender diversity. Recruiting participants from HS support groups likely over-sampled participants with longer HS diagnosis and, at least in our sample, potentially attracted participants with more advanced or severe HS. Thus, our study likely does not comprehensively capture quality of life and patient-provider communication concerns for individuals with Hurley stage I or less severe HS. Participants self-reported data on treatment options offered and accepted, as well as misdiagnoses, which also limits potential generalizability. Although participants did report anxiety and depression in open-ended questions about other health conditions, we did not include any specific measures of mental health conditions. Future studies should consider adding mental health measurements alongside the use of HiSQOL and other quality of life scales given what we already know about the negative impact of HS on mental health.

### Conclusions

Patients with HS experience a number of factors that negatively impact their mental health and quality of life, including delays in diagnosis, misdiagnosis, challenging interactions with providers, and barriers to communication with romantic partners. Data about delays in diagnosis and misdiagnosis for HS patients, specifically, indicate a need for further medical provider education about the condition. This also indicates a continued need for more research on HS treatments that may help alleviate physical symptoms of the condition, given that HS is understudied. Patients' negative responses to HS providers were related to negative responses to romantic partners, indicating that patient-provider communication may influence more than one aspect of well-being for patients. Providers should thus consider how patients experience patient-provider communication about HS, and how this communication impacts other areas of patients' lives, including quality of life, mental health, and romantic relationships. Future research should explore the ways in which providers may contribute to increased HS shame or stigma during their patient-provider communications, especially regarding the causes of HS or lifestyle changes recommended to patients. Special attention should focus on the multidimensional experiences of women with HS. Use of HiSQOL or other quality of life measures to assess impacts of HS across several domains can help providers better serve HS patients' unique needs.

Providers should prioritize mental health strategies in HS patients' care plans given this and other research showing the negative impacts of HS on mental health. Mental health prioritization is especially important for patients in later stages of HS who show decreased quality of life due to HS in our study. Providers should establish partnerships between dermatology practices and mental health professionals to aid in the multidisciplinary approach recommended for the treatment of HS. This can both increase communication between HS patients and their multiple providers, and decrease negative mental health outcomes for people living with HS.

### Conflicts of interest

None.

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### Study approval

N/A.

### Author contributions

NI: Conceptualization, data curation, funding acquisition, investigation, methodology, project administration, resources, software, supervision, writing - original draft, writing - review and editing. LRH: Conceptualization, funding acquisition, investigation, methodology, project administration, resources, supervision, writing - original draft, writing - review and editing. AW: Formal analysis, methodology, software, writing - original draft; writing - review and editing. CD: Writing - original draft.

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