

A New Tool to Improve Communication Between Hidradenitis Suppurativa Patients and Health Care Providers

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ABSTRACT

Background: Hidradenitis suppurativa (HS) patients tend to experience diagnosis delay, misdiagnosis, and embarrassment due to their condition. To address these issues, the International Dermatology Outcome Measure (IDEOM) HS Workgroup collaborated with patients to modify an existing Novartis questionnaire to better suit the needs of HS patients. This quality improvement project aimed to use the resulting Shine a Light on HS as Modified by the IDEOM HS Workgroup Questionnaire to enhance communication between HS patients and providers, improve clinical experience for HS patients, and gather relevant demographic data.

Method: Patients with HS presenting to Mount Sinai Union Square over a 9-month long period were invited to complete the Shine a Light on HS as Modified by the IDEOM HS Workgroup Questionnaire before seeing their providers. After the visit, patients rated their overall clinical experience and the helpfulness of the survey on a 5-point scale.

Results: The analysis cohort (n=30) consisted of a racially and ethnically diverse patient population. On a scale of 0-4, the mean helpfulness rating was 3.1 (SD=1), and the mean clinical experience rating was 3.5 (SD=0.78). There was a positive correlation between survey helpfulness and overall clinical experience and a moderately strong relationship by linear regression analysis ($r=0.73$, $R^2=0.53$). 80% reported frequent flares, 54% reported >10 years of symptoms, and the most commonly affected areas were the axillae, gluteal cleft, groin, and inguinocrural folds. The mean pain rating was 8 out of 10 (SD=2.55, Var=6.5). The majority of patients reported scars, tunnels, open wounds, ER/Urgent Care visits, inflammatory skin symptoms, and systemic symptoms. 39% had a positive HS family history. Biologics were the least common previous treatment reported (43%). Emotional burden was reported by nearly all patients, and comorbidities included depression, heart disease, arthritis, polycystic ovary syndrome (PCOS), diabetes, and irritable bowel disease (IBD).

Conclusion: The Shine a Light on HS as Modified by the IDEOM HS Workgroup Questionnaire was successful in improving HS patient-provider conversations, enhancing the overall clinical experience for HS patients, and collecting insightful demographic data. Healthcare providers should consider incorporating the questionnaire as part of their routine care for HS to enhance clinical discussion and improve outcomes for patients.

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INTRODUCTION

Hidradenitis suppurativa (HS) is a chronic, inflammatory skin condition characterized by abscesses, nodules, fistulae, draining sinus tracts, and scarring.¹ Though the pathogenesis of HS is not fully understood, the disease process centers around the pilosebaceous apocrine unit.¹ Thus, disease activity is generally high in the warm, wet areas, where these pilosebaceous-apocrine units are enriched, such as the axillae and the groin.² The condition can be severely disfiguring and be a source of embarrassment, pain, and diminished quality of life for patients.¹ HS is often misdiagnosed as abscesses, acne, or folliculitis.³ On average, it may take patients 10 years and seeing more than 3 different providers before receiving their correct HS diagnosis.³ This delay is associated with increased disease burden and quality of life impairment.³ Due

to patient embarrassment, frequent misdiagnosis, diagnosis delay, and disease severity, there exists a need to improve clinical discussion and experience for HS patients.

The International Dermatology Outcome Measure (IDEOM) is a nonprofit organization with the mission to establish patient-centered outcome measures within dermatology to improve both treatment and research efforts.⁴ The Shine a Light on HS Doctor Conversation Starter is a 15-item questionnaire developed by Novartis to help patients self-diagnose their HS and talk to their dermatologists about their symptoms. The IDEOM HS Workgroup modified this questionnaire. Patients and HCPs met at the 2022 IDEOM annual meeting and then subsequently worked to improve the questionnaire using

patient input. Through a multi-round process, the questionnaire was updated to better serve the needs of HS patients with targeted prompting for information important to providers and patients. The resulting 12-item questionnaire asks patients about their HS history, experience with the condition, and concomitant symptoms and diagnoses.

We launched a 9-month long quality improvement project using the Shine a Light on HS as Modified by the IDEOM HS Workgroup Questionnaire. Our quality improvement project had 3 specific aims: (1) To facilitate more productive

conversations between HS patients and their providers, (2) To improve the overall clinical experience of HS patients, and (3) To collect relevant demographical data characterizing the HS history of the patients presenting to a tertiary care center.

MATERIALS AND METHODS

Patients with HS presenting to the Mount Sinai Union Square tertiary care center from July 2022 to March 2023 were identified by chart review and asked to complete the 12-item Shine a Light on HS as Modified by IDEOM HS Workgroup Questionnaire at the clinic before seeing their providers. All patients with HS

FIGURE 1. The Shine a Light on HS as Modified by the IDEOM HS Workgroup Questionnaire.

Shine a light on HS as modified by the IDEOM HS workgroup. June 2022.

Get help navigating your skin condition by answering a few of these questions. Talking about your symptoms—and the impact they're having on your life—with a dermatologist who has experience diagnosing and treating hidradenitis suppurativa (HS) can help.

Tell your doctor (primary care, OB/GYN or dermatologist) about any bumps, boils, or abscesses (for children, include pimples and blackheads not only on the face) you've experienced over the 6 months.


If possible, take a few photos of your skin signs with your phone and bring them with you to show your doctor.

1. How many times have these bumps, boils, or sores (abscesses) occurred over the past 6 months?

☐ 1-2 times ☐ 3-4 times ☐ More than 5 times

2. How many years ago did you first notice symptoms?

3. Circle all the areas of your body that have been affected:



Tell your doctor how these symptoms make you feel physically.

4. Check all the symptoms that you have experienced with the bumps, boils or sores (abscesses):

☐ Pain ☐ Swelling ☐ Itching
☐ Leakage or draining pus and/or blood
☐ Odor ☐ Joint pain ☐ Redness
☐ Fatigue ☐ Inflammation
☐ Other: _____

5. If these symptoms cause pain, how bad is it? Select the number that reflects the extent of the pain. (0 – No pain; 10 – Worst pain imaginable)

0	1	2	3	4	5
6	7	8	9	10	

6. How have these bumps, boils, or sores (abscesses) affected your skin? Check all that apply.

☐ They have left scars
☐ They have caused tunnels (also called sinus tracts) underneath my skin that drain when pressed
☐ Open Wounds
☐ Other: _____

Tell your doctor about your medical history and family history.

7. Have you had to visit the emergency room or urgent care because of your symptoms in the last year?

☐ Yes ☐ No

If yes:
How many times? _____
What did they do for you there?

Where are your medical records and are they available?
☐ Yes ☐ No

8. Has anyone else in your family had similar symptoms?

☐ Yes ☐ No

How have you managed your symptoms in the past?

9. Check any treatment that you have used or that have been prescribed to you:

☐ Over-the-counter NSAIDs for pain relief (e.g., acetaminophen, ibuprofen)
☐ Over-the-counter creams/ointments
☐ Prescription corticosteroid creams/ointments
☐ Antibiotics
☐ Incision and drainage
☐ Injections into lesions
☐ Biologics
☐ Home remedies
☐ None of the above
☐ Other: _____

Tell your doctor how your symptoms have impacted your life.

10. Describe how your symptoms have impacted you emotionally. Have your symptoms made you (Check all that apply):

☐ Feel down or depressed
☐ Feel embarrassed
☐ Feel anxious or nervous
☐ Lack sexual desire
☐ Poor self image
☐ None of the above
☐ Other: _____

11. Describe any other ways that your life has been negatively affected by your symptoms. Check all that apply.

☐ Sleep
☐ Bathing
☐ Choosing what to wear
☐ Going to work
☐ Ability to study or concentrate
☐ Physical activity (or exercise)
☐ Avoiding social events
☐ Missing family activities
☐ Relationships
☐ Engaging in sexual activity
☐ Financial
☐ Water sports
☐ Other: _____

12. Have you been diagnosed with any of the following medical conditions? Check all that apply.

☐ Heart disease
☐ Diabetes
☐ Polycystic ovary syndrome
☐ Inflammatory bowel disease
☐ Arthritis
☐ Depression
☐ Other: _____

Additional notes to talk over with your doctor:

Please answer the following questions at the end of your visit today.

On a scale of 0 – 4, how helpful was this survey in facilitating your conversation about your HS with your doctor today? Circle the number that best describes your evaluation.

Not Helpful 0 Barely Helpful 1 Helpful 2 Quite Helpful 3 Very Helpful 4

Please rate your overall clinical experience today on a scale of 0 – 4. Circle the number that best agrees with your rating.

Poor 0 Fair 1 Good 2 Very Good 3 Excellent 4

were invited to participate with no exclusion. Repeat clinic visitors were invited to participate only once. Specifically, the questionnaire (Figure 1) asked patients about symptom incidence, condition duration, body areas affected, symptoms experienced, pain, skin impact, ER or urgent care visits, HS family history, prior treatments, emotional impact, breadth of symptom impact, and medical history.

After seeing their providers, patients were asked to complete 2 quality measure questions. They were asked to rate both the “helpfulness of the survey in facilitating their conversation about their HS with their provider” and their “overall clinical experience” on a 5-point scale from 0 to 4 (0: Not helpful/Poor, 1: Somewhat helpful/Fair, 2: Helpful/Good, 3: Quite helpful/Very good, 4: Very helpful/Excellent).

Incomplete questionnaires were included in the analysis if the 2 quality measure questions were answered. Descriptive statistics and content analysis were used to analyze quantitative and qualitative data, respectively.

RESULTS

Respondents included 30 patients for a response rate of 91%. The overwhelming majority (97%) of patients reported the survey was helpful to very helpful with a rating of 2-4. The mean rating was 3.1 with a standard deviation of 1.0. Additionally, 100% of our patients reported a clinical experience that was good to excellent with a rating of 2-4. The mean rating was 3.5 with a standard deviation of 0.78. There was a positive correlation between survey helpfulness and overall clinical experience ($r=0.73$). Linear regression analysis revealed a moderately strong relationship ($R^2=0.53$). Results from our 2 quality improvement measure questions are summarized in Table 1.

TABLE 1.

Response Summary for Quality Improvement Measure Questions		
	Survey Helpfulness	Overall Clinical Experience
Rating		
0	0% (n=0)	0% (n=0)
1	3% (n=1)	0% (n=0)
2	37% (n=11)	17% (n=5)
3	3% (n=1)	20% (n=6)
4	57% (n=17)	63% (n=19)
Mean	3.1	3.5
Standard Deviation	1.0	0.78
Variance	1.1	0.60
Median	4	4
Mode	4	4

We were also able to collect important demographical information about our HS patient population and their symptom history and burden. The mean age of our patients was 37 years old with a female to male ratio of 4:1. Our patient population demonstrated both racial and ethnic diversity with patients self-identifying their race as African American (43%), White (10%), Asian (6%), and Other (40%) and their ethnicity as Hispanic (27%), Non-Hispanic (47%), and Unknown (27%). The demographic distribution of our patients is summarized in Table 2. 80% of our patients reported more than 5 instances of symptom flare over the last 6 months. At least 54% of our patients have been experiencing symptoms for 10 years or more. In order, the most commonly affected areas were the axillae (77%), the gluteal cleft (60%), the groin (53%), and the inguinocrural folds (43%). The overwhelming majority of our patients experienced inflammatory skin symptoms, such as redness, pain, leakage, swelling, inflammation, itching, and odor. A majority of our patients also experienced systemic symptoms such as fatigue (57%) and joint pain (43%). On a pain scale of 0-10, the mean pain rating was 8 (SD=2.55, Var=6.5). The overwhelming majority of our patients reported their HS caused scars, tunnels, and open wounds. 53% of our patients have had to visit the ER or Urgent Care due to their HS over the last year. 39% of our patients reported a positive HS family history. The most common previous treatments were antibiotics (83%), injections into lesions (67%), OTC NSAIDs (63%), prescription corticosteroid creams/ointments (63%), and incision and drainage (63%). Biologics were the least common previous treatment reported (43%). Nearly all patients reported significant emotional burden from their HS and are impacted across all domains of their lives. Patients reported comorbidities of depression (50%), heart disease (17%), arthritis (13%), PCOS (13%), diabetes (10%), and IBD (7%). The survey responses characterizing the HS history, burden, and symptom impact of our HS patient population are summarized in Table 3.

TABLE 2.

Patient Demographics		
Age	Mean: 37 years	
Gender		
Female	80%	(n=24)
Male	20%	(n=6)
Race		
African American	43%	(n=13)
White	10%	(n=3)
Asian	6%	(n=2)
Other	40%	(n=12)
Ethnicity		
Hispanic	27%	(n=8)
Non-Hispanic	47%	(n=14)
Unknown	27%	(n=8)

TABLE 3.

Survey Responses Characterizing HS History Summary			
Characteristics	n (%)	Characteristics	n (%)
HS History		HS History (continued)	
Symptoms over past 6 months		HS Family History	
1-2 times	3 (10)	Yes	11 (39)
3-4 times	3 (10)	No	17 (61)
>5 times	24 (80)	Previous treatments	
Years since symptom onset		Antibiotics	25 (83)
<5 years	4 (17)	OTC NSAIDs	20 (67)
5-9 years	7 (29)	Injections	20 (67)
>10 years	13 (54)	Prescription corticosteroid creams/ointments	19 (63)
Affected body areas		Incision & drainage	19 (63)
Axillae	23 (77)	OTC creams/ointments	15 (50)
Gluteal cleft	18 (60)	Home remedies	15 (50)
Groin	16 (53)	Biologics	13 (43)
Inguinocrural folds	13 (43)	Other	3 (10)
Buttocks	11 (37)	None of the above	2 (7)
Submammary	10 (33)	Emotional impact	
Legs	7 (23)	Down/depressed	18 (60)
Back	6 (20)	Embarrassed	24 (80)
Abdomen	5 (17)	Anxious/nervous	19 (63)
Suprapubic	4 (13)	Lack of sexual desire	16 (53)
Breast	4 (13)	Poor self-image	19 (63)
Chest	3 (10)	None of the above	3 (10)
Face	3 (10)	Impact on quality of life	
Intermammary	2 (7)	Sleep	21 (70)
Feet	1 (3)	Bathing	20 (67)
Scalp	1 (3)	Choosing what to wear	26 (87)
Symptoms		Going to work	13 (43)
Pain	28 (93)	Ability to study/concentrate	17 (57)
Swelling	26 (87)	Physical activity/exercise	22 (73)
Itching	24 (80)	Avoiding social events	12 (40)
Leakage/draining	28 (93)	Missing family activities	12 (40)
Odor	24 (80)	Relationships	18 (60)
Redness	29 (97)	Engaging in sexual activity	19 (63)
Inflammation	26 (87)	Financial	15 (50)
Fatigue	17 (57)	Water sports	9 (30)
Joint pain	13 (43)	Past Medical History	
Skin impact		Heart disease	5 (17)
Scars	29 (97)	Diabetes	3 (10)
Tunnels	23 (77)	PCOS	4 (13)
Open wounds	23 (77)	IBD	2 (7)
ER/Urgent Care in last year		Arthritis	4 (13)
Yes	16 (53)	Depression	15 (50)
No	14 (47)		

DISCUSSION

We were able to characterize significant HS historical information about our diverse patient population seeking care from a renowned HS specialist at a tertiary care center. As such, many of our patients experienced significant disease burden, the severity of which frequently goes overlooked. Nearly all patients identified significant morbidity and impact across all domains of their lives. The emotional impact of HS is often under-appreciated, but more than half of our patients have been diagnosed with depression. Heart disease, arthritis, PCOS, diabetes, and IBD were other commonly reported comorbidities, suggesting that clinicians should support screening for these conditions as a part of comprehensive care. Though the overwhelming majority of our patients report having active disease with a mean pain rating of 8, less than half of them have been treated with biologic medications. The subset of patients who tried biologics were characterized by the following: 54% of those with >5 flares in 6 months, 62% of those with >10 years of symptoms, and 41% of those with a pain rating of >8. With adalimumab already FDA-approved for HS and novel biologics coming to market, these numbers expose a potential gap in care for patients who are failing their current therapies. Our survey results underscore the necessity of improving HS patient care.

The overwhelming majority of our patients found the Shine a Light on HS as Modified by the IDEOM HS Workgroup Questionnaire helpful to their clinic visit. This sentiment positively correlated with overall clinical experience. It is important to note that patients were visiting a tertiary care center to be seen by an HS specialist, so patient-provider conversation at baseline is likely above average when compared to non-specialist counterparts. As such, while our results are impressive, they may underestimate the value of this survey. Potential applications to maximize the utility of the Shine a Light on HS as Modified by the IDEOM HS Workgroup Questionnaire include general dermatology, private practice dermatology, family medicine clinics, OBGYN clinics, and primary care practices where providers may not be as well versed in HS. The survey can be downloaded free of charge on the IDEOM website (<https://www.dermoutcomes.org/workgroups/hidradenitis-suppurativa.php>).

DISCLOSURES

Melissa Peri Zundell has no conflicts to disclose. Alice B. Gottlieb has received honoraria as an advisory board member and consultant for Amgen, AnaptysBio, Avotres Therapeutics, Boehringer Ingelheim, Bristol-Myers Squibb, Dice Therapeutics, Dermavant, Eli Lilly, Janssen, Novartis, Pfizer, Sanofi, Sun Pharma, UCB, and Xbiotech and has received research/educational grants from AnaptysBio, Moonlake Immunotherapeutics AG, Novartis, Bristol-Myers Squibb, and UCB Pharma, (all paid to Mount Sinai School of Medicine).

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