DERMATOLOGY CLINICAL IMMERSION SERIES

Issue 03

# A Window of Opportunity in HS:

## Recognizing Progression, Understanding Impact, and Implementing Timely Management


### HS: A Progressive and Heterogeneous Disease That Requires an Early Diagnosis

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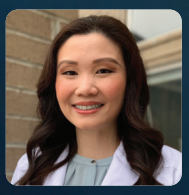

### The Impact of HS

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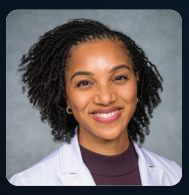


### Managing HS: A Multimodal and Collaborative, Patient-Centered Approach

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# Foreword

Hidradenitis suppurativa (HS) is a chronic, systemic, and inflammatory condition that is associated with a significant quality-of-life impairment. HS can impact patients physically, psychologically, socially, and professionally.

This booklet features 3 articles focused on the heterogeneous and progressive nature of HS, the impact that HS can have on patients, and management strategies that, if initiated within a window of opportunity, may help provide therapeutic benefit to patients and help reduce irreversible tissue damage.

## HS: A Progressive and Heterogeneous Disease That Requires an Early Diagnosis

**Authors:** Kimberly L. Brown, MMS, CPAAPA, PA-C, & Patricia M. Delgado, DNP, APRN, DCNP

Hidradenitis suppurativa (HS) is a chronic, systemic, and inflammatory condition characterized by recurrent painful nodules, abscesses, and tunnels in the skin.[1] It is widely documented that HS can have a significant impact on the lives of patients, including their school, work, mental health, and relationships.[2] For example, patients with HS often suffer from depression, anxiety, loneliness, and isolation, and are more likely to be unemployed than the general population.[3-7] Consistent with the systemic nature of this disease, HS is associated with a high comorbidity burden and increased mortality.[8,9] The first in the series, this article explores the heterogeneous and progressive nature of HS and the importance of starting treatment early to help reduce irreversible tissue damage.

> *"HS is a progressive disease, so for me, a success story is being able to diagnose and appropriately treat HS early. A recent success story involves early recognition, diagnosis, and treatment of HS with a biologic much earlier than usual. The patient was excited to wear a bathing suit again, and so far, she hasn't had to return to the emergency room for her HS."*
>
> – Kimberly L. Brown, MMS, CPAAPA, PA-C

### Epidemiology and risk factors of HS

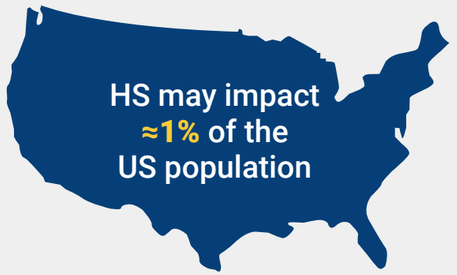
Although the true prevalence of HS is not known, as it varies based on the use of diverse methods and data sources, HS may impact approximately 1% of the US population **(Figure 1)**.[10,11] The prevalence of HS is greater among younger patients, and the onset of HS typically occurs in young adulthood or after puberty.[12,13] Demographically, HS impacts **women 3 times** more often than men.[14] However, men are more likely to have severe disease.[15] While HS can occur in all ethnicities, **African Americans are disproportionately affected** in the United States **(Figure 1)**.[12] Moreover, a recent study showed that African American patients were more likely to have severe disease when compared with Caucasian patients and were more at risk for HS-related emergency department visits, hospitalizations, and surgery than Caucasian patients.[15]

Up to 30% of patients report a family history of HS.[8,16] However, genetic factors contributing to the development of HS remain unknown.[8] Several studies have reported loss-of-function mutations in the gene encoding γ-secretase in patients with HS.[8,17]

However, most patients with a family history of HS do not carry γ-secretase mutations, and no genetic cause has been described for sporadic HS, which comprises the majority of HS cases.[8]

**Figure 1**

**THE PREVALENCE OF HS IN THE UNITED STATES IS ESTIMATED TO BE AROUND 1%**




***HS also may affect nonsmokers with normal weight***

- **Women** are 3x more likely to develop HS
- **African Americans** are **disproportionally affected** in the United States
- Up to **30%** of patients may have a **family member** with the condition
- More than **75%** of patients with HS may be **overweight** and **obese**
- **Smokers** may be **more at risk** for severe disease compared with nonsmokers

> *"Every time I diagnose HS, I tell patients to start talking to their family. Most patients tell me they are the only one in their family with HS, but I say, 'Start asking people, and when you come back to me, you tell me if there's somebody else in your family with this condition.' My patients almost always have a family member affected."*
>
> – Kimberly L. Brown, MMS, CPAAPA, PA-C

Lifestyle factors have been associated with the development of HS. Smokers may be more at risk for severe disease compared with nonsmokers.[18] Obesity is another identified risk factor for HS.[19] Despite that, the evidence supporting weight loss and smoking cessation as a means of improving the clinical course of HS is limited.[20] **In addition, nonsmoking patients with a normal weight also may develop HS.**[21] In fact, severe HS affecting the nape of the neck has been described in men with a lower body mass index.[22]

### HS is associated with a significant diagnostic delay

HS is associated with a delay of up to 10 years from disease onset to diagnosis, largely due to low recognition of the condition and misdiagnoses outside of the dermatology setting.[8,23,24] Before receiving an accurate HS diagnosis, patients with HS may see up to 10 providers, which can include primary care, surgery, obstetrics/gynecology, emergency medicine, and urgent care providers.[13,23-26] However, in some cases, accurate diagnoses may even be delayed in the dermatology office if dermatologists or advanced practice providers (APPs) are not familiar with diagnosing and treating HS.[13]

**The 3 key elements for diagnosing HS include determining the type of lesions, the location of lesions, and the chronicity of the condition.**[27] The characteristic distribution of lesions in HS and the peripubertal onset of the disease help providers distinguish it from other dermatological conditions with similar morphology, such as acne **(Figure 2)**.[19,28] When you see patients with dermatological conditions that may mimic HS, consider asking them the following question:

***"Have you had outbreaks of boils during the last 6 months, with a minimum of 2 boils, in one of the following locations: axilla, groin, genitals, under the breasts, or other locations, such as perianal, neck, or abdomen?"***[29,30] One study reported that this question has a sensitivity of 90%, a specificity of 97%, and a positive predictive value of 96%.[30]

Despite the existing diagnostic criteria, studies show that patients with the longest diagnostic delays can receive up to 5 misdiagnoses before receiving an accurate HS diagnosis.[13] This may be due to the lack of recognition of HS among routine care providers who may see patients with HS first.

Typical locations for HS lesions include the axillae, under the breasts, and groin **(Figure 3)**.[14] However, in rare cases, HS lesions may be present in atypical sites, including the chest, face, eyelids, scalp, retroauricular and preauricular skin, thighs, and abdomen.[31] HS also may affect the jawline, posterior neck, and the umbilicus.[31,32]

*"I think dermatology does a good job of diagnosing HS; however, if a patient comes in with one abscess but doesn't share that they are repetitive, the diagnosis could be easily missed. So we have to ask more questions to elicit history."*

– Kimberly L. Brown, MMS, CPAAPA, PA-C

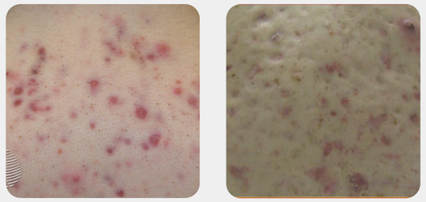
*"Because HS isn't as rare as we once thought, I often consider it when seeing patients for other conditions in other anatomical locations. Because HS can often be misdiagnosed as acne or folliculitis, ask them if anything else is going on in places where the sun doesn't shine: the genitals, under the arms, and the lower abdomen."*

– Patricia M. Delgado, DNP, APRN, DCNP

## Figure 2

**COMMON MISDIAGNOSES FOR HS INCLUDE**

- Abscess
- Cellulitis
- Inflamed cyst
- Furuncle and carbuncle
- Pilonidal sinus
- Sexually transmitted infection



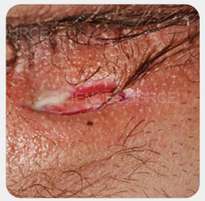
ACNE



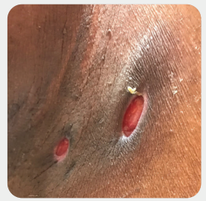
HS

*Left image provided by DermNet New Zealand.*
*Right image provided by* Dermatology Online Journal, *copyright Noah Scheinfeld, MD.*

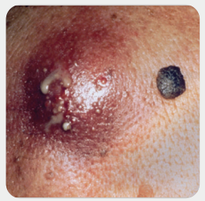
Acne frequently appears on the face, back, and upper chest and shares common features with HS—pustules, inflammatory nodules, and scarring.



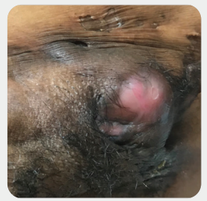
PERIANAL ABSCESS



HS



CARBUNCLE



HS

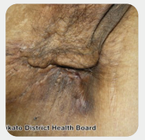
*Left images are provided by Science Source.*
*Right images are provided by Dr Moiin.*

Abscesses and carbuncles of infectious origin are transient, with a random distribution, while HS abscesses occur in intertriginous areas.

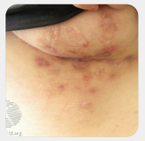


## Figure 3

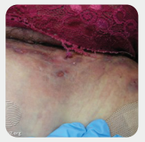
**TYPICAL LOCATIONS OF HS**



HS lesions in the axilla



HS lesions under the breast



HS lesions in the groin

*Images provided by DermNet New Zealand.*

# HS is a progressive disease and requires timely intervention

*"We have been able to follow patients very closely, and I've noticed that flares will occur more frequently as the disease progresses. In addition, the inflammation will last longer, or it will become increasingly more severe. And unfortunately, sometimes a new lesion will appear in an area where the patient had not previously been affected."*

– Patricia M. Delgado, DNP, APRN, DCNP

HS can be a progressive condition, and early diagnosis is critical to help minimize the consequences of this often stigmatizing and painful disease.[18,33]

In the beginning, patients may experience discomfort, erythema, burning, pruritus, or hyperhidrosis.[16] Patients may present with inflammatory nodules that may tingle or burn.[27] Further progression can present as deep dermal abscesses that may join and form draining sinus tracts.[27] Increasing disease severity also may start to affect the quality of life of patients with HS, with the presence of symptoms such as pain, soreness, stinging, or itching, as well as embarrassment.[34]

Severe HS is associated with frequent flares, draining sinus tracts, incomplete healing, ropelike scars, and extensive sinus networks extending into tissue.[27,35] Scarring can be irreversible.[36]

Most patients have moderate or severe disease at diagnosis **(Figure 4)**.[13,37] Moreover, rapid progression from mild to moderate disease is a predictive factor for developing severe HS **(Figure 4)**.[38] If progression to a more severe disease stage occurs, the skin damage may be irreversible.[37]

There are multiple approaches to gauging severity of HS, and Hurley staging is one method. Hurley staging has been used to describe the progression and severity of HS:

- Hurley stage I is associated with the formation of abscesses (single or multiple), without sinus tracts or scarring.[37]
- Hurley stage II is characterized by recurrent abscesses (single or multiple) and widely separated lesions, with tunnel formation and/or scarring.[37]
- Hurley stage III presents with diffuse involvement of multiple interconnected tunnels and abscesses across the entire area.[37]

Hurley staging, however, is a static picture of the disease and may not fully represent the severity of this complex and dynamic condition.[39] **Mild, moderate, or severe HS also may correspond to the degree to which the disease impacts patients' quality of life.** Several management guidelines recommend incorporating patient-reported outcomes, such as pain and the Dermatology Life Quality Index (DLQI), into assessments, along with Hurley staging.[40]

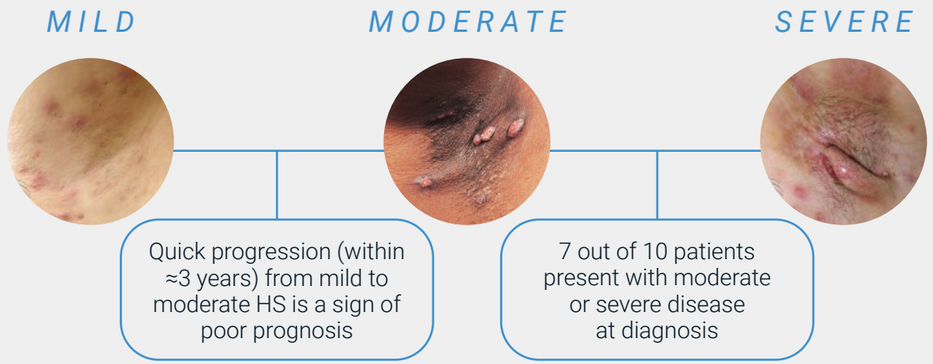
*"Frequent cycles of inflammation and healing may lead to permanent irreversible scarring and fistulas. Complete removal is only possible with surgical revision. Keep in mind that if HS is not identified and treated early on, any lesion could eventually become a cause of irreversible damage."*

– Patricia M. Delgado, DNP, APRN, DCNP

Prompt diagnosis and initiation of treatment may be critical to help slow the progression of HS to severe disease with fibrotic or clinically irreversible lesions.[16,41] In fact, a recent study found an inverse correlation between therapeutic delay and the clinical response to treatment, suggesting that there is a window of opportunity during which appropriate treatment might provide the maximum therapeutic benefit to patients.[42] This suggests that treatment initiated during earlier stages of the disease can help slow its progression to more severe stages.

## Figure 4

**HS CAN BE A PROGRESSIVE DISEASE, AND RAPID PROGRESSION FROM MILD TO MODERATE STAGE IS A STRONG PREDICTOR FOR DEVELOPING SEVERE HS***




*Mild and severe: images of axillae of patients with HS provided by DermNet New Zealand. Moderate: image of axilla of a patient with HS provided by Science Source.*

**HS progression rate was retrospectively studied in 225 patients who filled out a supervised questionnaire, with disease severity (Hurley stage) determined by a dermatologist. Photographs, which were validated for self-assessing the Hurley stage, were accompanied by an oral explanation to help patients recall the time of progression to each Hurley stage.*

## Conclusion

Associated with a long diagnostic delay, HS is a heterogeneous condition that can be progressive. Understanding the signs and symptoms of HS along with atypical presentations of HS is essential for early and timely diagnosis of this often debilitating disease. Early diagnosis and initiation of appropriate treatment may be critical to help reduce irreversible tissue damage. Dermatologists and dermatology APPs are uniquely positioned to identify HS early and develop effective treatment plans.

## Key Takeaways

1. HS can be associated with a long diagnostic delay, contributing to greater disease severity, comorbidity burden, and increased likelihood of HS surgery.
2. Symptom control is most effective when initiated early, ideally within the window of opportunity, to help slow the progression of this often painful and stigmatizing condition and to help reduce irreversible tissue damage.

# The Impact of HS

**Authors:** Amit Garg, MD, & Vivian Y. Shi, MD

Hidradenitis suppurativa (HS) is a chronic, systemic, and inflammatory condition that can profoundly impact patients' lives.[43,44] This article, the second in the series, reviews the impact HS can have on patients and discusses strategies that dermatologists and dermatology advanced practice providers (APPs) can use to develop effective management plans to help patients reduce the impact on their daily lives.

## HS can be a painful and stigmatized condition

Most patients begin experiencing symptoms in young adulthood or after puberty but may not receive a formal diagnosis of HS for up to 10 years after symptom onset.[13,23,26] Consider that in those 10 years, many people graduate from college or graduate school, accept their first job, get married, and buy their first home. For patients with HS, however, this period may be marked by disease flares that cause extreme pain, frustration with misdiagnoses or treatment failures, and impaired quality of life.[13,23,43,45] Not only does HS impact patients' physical and psychological well-being, but it also may impact their social interactions and professional advancement.[2,3,7,23,46-48] In addition, HS is associated with a large comorbidity burden, further compounding the impact that this condition can have on patients.[9]

Unfortunately, many patients with HS may not see a healthcare professional for approximately 2 years after symptoms first appear.[26] During this time, many attempt self-management of their symptoms.[47] This delay can be attributed to patient embarrassment, especially if lesions appear in sensitive areas, and a sense of isolation—testaments to the emotional toll HS can take on patients.[46,48-50]

## Pain can substantially contribute to reduced quality of life in patients with HS

> *"It feels like you are being stabbed or like you just got a cut. And then, it's very sore, to the point where [if] you even move, it is going to hurt even worse. I would be in my room crying and rocking back and forth because the pain was so bad."*
>
> – Patient with HS[51]

HS may affect patients physically, psychologically, socially, and professionally.[2,3,7,23,46-48] Patients frequently mention the physical impact of their symptoms, with the most bothersome symptoms including pain, discharge, and itch **(Figure 1)**.[46,47] Pain can have a significant impact on the lives of patients with HS because it may prevent them from performing routine tasks, such as dressing and moving around.[46] These limitations may create a feeling of helplessness and dependency on other people and take away a patient's feeling of control.[46]

> *"In terms of most bothersome symptoms, pain and drainage are no-brainers, but I can't tell you how much patients complain about itching, especially African American patients who form keloids and very exuberant scarring around their HS site."*
>
> – Vivian Y. Shi, MD

According to one study, patients with HS experience more emergency department visits and hospitalizations compared with a control group and patients with other dermatological conditions, such as psoriasis.[52]

There are 2 types of pain related to HS—nociceptive and neuropathic—and patients with HS may experience both.[53] Nociceptive pain often occurs in response to tissue injury, when signaling molecules at the site of tissue injury induce pain.[53]

In HS, nociceptive pain likely results from acute inflammation.[53] In contrast, neuropathic pain stems from somatosensory nervous system dysfunction.[53] In HS, neuropathic pain may result from chronic inflammation that leads to peripheral neuroplastic changes and central sensitization.[53] Patients with HS might benefit from a long-term management strategy that considers both types of pain.[53]

> *"Some providers believe that if you treat tissue damage and the acute pain in HS, patients will get better. But the neuropathic pain is often forgotten."*
>
> – Vivian Y. Shi, MD

Figure 1

**PHYSICAL IMPACT OF HS**

Pain | Discharge | Itch

**≈97%**

*OF PATIENTS REPORT PAIN ASSOCIATED WITH HS*

**>75%**

*OF PATIENTS WITH HS MAY NOT RECEIVE PAIN MANAGEMENT*

## HS has a profound mental health impact

> *"There is not nearly enough support for the detrimental mental aspects that are involved in living with HS, as it is swept under the rug in the United States."*
>
> – Patient with HS[54]

Physical symptoms associated with HS take a toll on the mental health of patients. Patients with HS experience higher rates of depression, suicide, and substance-related disorders **(Figure 2)**.[3,20,55,56]

Anxiety and depression in patients with HS, as assessed by the Hospital Anxiety and Depression Scale, were higher compared with control subjects.[7] While depression generally increases with more severe disease, even patients with mild to moderate HS may report mental health scores that are similar to those of patients with depression, as measured on the 36-Item Short Form Health Survey (SF-36).[7,57]

The physical and psychological symptoms of HS may create a vicious cycle. Physical symptoms, including pain, may contribute to the onset of depressive symptoms or may aggravate existing symptoms of depression. In addition, patients with HS may avoid social interactions to cope with the disease and reduce embarrassment, which may contribute to depressive symptoms.[51] Similarly, patients with HS, who experience chronic pain and report a significant psychological impact due to the disease, may have an increased risk for substance use disorder.[56]

Despite the established prevalence of psychiatric comorbidities among patients with HS, patients report that mental health support is an unmet need in their care.[51,54]

Figure 2

**PSYCHOLOGICAL IMPACT OF HS**

Depression | Suicide | Substance Misuse

**43%**

*OF PATIENTS WITH HS HAVE DEPRESSION*

**1.5x**

*INCREASED RISK OF SUBSTANCE MISUSE*

**2x**

*INCREASED RISK OF COMPLETED SUICIDE VS GENERAL POPULATION*

## Social aspects of patients' lives are impacted by HS

> *"[I feel] like a terrible person, like an animal…. I don't like myself, so what can I give to anyone else?"*
>
> – Patient with HS[58]

In addition to the profound physical and psychological impact of HS, this disease impacts patients' relationships with others **(Figure 3)**.[59]

In one study, patients with HS presented with higher loneliness and isolation scores compared with a control group.[7] Patients with HS report that the condition has a negative impact on their relationships, and they may find intimate relationships particularly troublesome because their lesions are difficult to explain. As a result, patients with HS may push people away.[46,59] Scars and deformation also may cause feelings of embarrassment for patients with HS.[46] Malodor is another key symptom of HS that may affect the social lives of patients with HS.[60,61] Malodor is associated with higher body mass index, disease duration, the number of affected regions, Hurley stage, and the intensity of suppuration.[60,61] Malodor may have a significant impact on the quality of life of patients with HS.[60,61]

Sexual dysfunction, defined as any difficulty experienced by an individual or couple during normal sexual activities, is prevalent among patients with HS.[48] Patients with HS are ≈40% more likely to experience sexual dysfunction compared with the general population.[48]

> *"We don't ask about [sexual dysfunction] enough. Many patients don't have children, and it may not only be due to hormonal and metabolic burden. But they often have difficulties establishing and maintaining a relationship and, therefore, they don't end up having children. They want to have a relationship. They can't. They want to be intimate. They can't."*
>
> – Vivian Y. Shi, MD

Figure 3

**SOCIAL IMPACT OF HS**

Social Isolation | Loneliness | Sexual Dysfunction

**46%**

*OF PATIENTS WITH HS REPORT A NEGATIVE IMPACT ON THEIR RELATIONSHIPS*

**≈50%**

*OF PATIENTS WITH HS REPORT SEXUAL DYSFUNCTION*

## HS takes a toll on the professional lives of patients

> *"I have made career choices and avoided greater work responsibilities just to accommodate my HS because I cannot have others relying on my ability to work."*
>
> – Patient with HS[54]

Furthermore, HS can impact patients' professional lives. Many patients with HS report missing work due to flares, and approximately 1 in 4 patients are unemployed **(Figure 4)**.[2,4] In one study, 10% of employed patients were dismissed from work during 2 years of follow-up because of their inability to perform their duties and/or because of frequent absences, and around 23% of employed patients with HS reported obstacles related to promotion and advancement.[43]

Figure 4

**PROFESSIONAL IMPACT OF HS**

Unemployment | Frequent Absences | Lack of Advancement

**25%**

*OF PATIENTS WITH HS ARE UNEMPLOYED*

**>50%**

*OF PATIENTS WITH HS REPORT MISSING WORK*

The professional impact of HS has financial consequences for patients. According to a recent study, patients with HS have lower annual income and income growth compared with a matched control population.[62] In addition, they face higher annual costs, compounding the financial burden of HS.[62]

## The impact of HS extends beyond the patient

HS can affect partners of patients with HS. In fact, over 80% of partners of patients with HS report some degree of impact on their quality of life.[63] Partners of patients with HS experience increased household expenditures, emotional distress, and impairment in recreational or leisure activities. They spend more time looking after their partner.[63] Their physical well-being and personal relationships also may be affected.[63] Partners of patients with HS may have to do extra housework and spend a lot of time helping the patient with care duties and personal hygiene.[63]

## Dermatologists and dermatology APPs can help mitigate the impact of HS

The impact of HS on various aspects of patients' lives underscores the need for comprehensive management. Across clinical guidelines, recommendations for HS management endorse a multidisciplinary approach and collaboration among providers to manage the cutaneous and extracutaneous manifestations of HS.[40]

Most often provided by a dermatologist, appropriate medical care can help mitigate the physical symptoms of HS, including inflammatory nodules, draining sinus tracts, and pain.[23] HS management guidelines in dermatology recommend the monitored use of nonopioid analgesics such as NSAIDs, topical agents, and alternative therapies for mild to moderate pain.[51] For HS pain not alleviated by standard treatments, partnership with pain management or physical therapy specialists may be considered.[45]

There are currently no available recommendations for specific psychosocial interventions in the treatment of patients with HS.[51] However, the US and Canadian Hidradenitis Suppurativa Foundations recommend screening patients with HS for psychological comorbidities, such as anxiety and depression, as well as for suicidal ideation for patients with known psychiatric disease or those who exhibit signs of psychological distress.[20] Screening for substance misuse also is recommended, especially for patients with chronic pain, depression, and anxiety.[20] These recommendations highlight the mental health and substance misuse burden on patients and the importance of a multidisciplinary approach to care for patients with HS, including appropriate and timely psychiatric referral.[56]

However, there are some strategies to improve the well-being of patients that begin in the dermatology clinic.

One strategy that can help providers decrease morbidity associated with HS and improve clinical outcomes is counseling patients on appropriate undergarment styles and clothing fabrics that can reduce friction and irritation at affected sites and help decrease the frequency of HS flares.[64] For example, quality fabrics, such as rayon, cellulose-based Tencel, Lyocell, 100% cotton, and bamboo-based fabrics, can provide improved temperature control, softness, absorbency, and durability.[64]

To collaborate with patients on HS management plans, consider leveraging existing programs and resources to address the needs of vulnerable populations, such as children, pregnant women, underrepresented minorities, and patients with a low socioeconomic status.[45] For example, consider directing patients with low socioeconomic status to patient assistance programs or suggesting affordable dressing alternatives.[45]

**Finally, to minimize the psychological impact of HS, providers may consider waiting to discuss sensitive topics, such as weight loss or smoking cessation, until a therapeutic alliance with the patient has been established.**[45]

> *"The relationship between smoking and obesity with HS is complex. We don't yet know if smoking cessation or weight loss changes the course of disease in HS, but we do know these are important to improving general health status. I prefer not to discuss smoking, diet, nutrition, or weight loss until I have established a therapeutic relationship with the patient, because it's also important that patients don't feel blamed by us for having contributed to their HS in some way."*
>
> – Amit Garg, MD

Many patients with HS have had negative experiences with the healthcare system, contributing to mistrust of the medical community, which may lead to lower treatment adherence.[45] Routinely assessing pain level at clinic visits and acknowledging suffering can help establish a positive relationship built on rapport and trust.[45] Communicating to patients that HS is a systemic disease and, importantly, not their fault also may help build trust. Virtual or local HS support groups can help patients receive continued support outside the clinic setting.[45]

> *"Support groups are a vital resource for patients with HS who are struggling with managing their disease and its impact. Fortunately, we have high-quality patient advocacy organizations that can provide peer-to-peer support to patients, and dermatologists should become familiar with them so that we can direct our patients to these resources."*
>
> – Amit Garg, MD

Consider directing patients with HS to the HS Foundation website, which contains valuable resources for patients, including educational materials related to HS and information on HS specialty clinics and HS support groups: https://www.hs-foundation.org.

## Conclusion

HS is a chronic and often debilitating condition that has a significant impact on patients' quality of life. Patient-centered care that considers the effects of HS that extend beyond the skin may help minimize this impact and improve patients' lives.

## Key Takeaways

1. HS can have a significant impact on the quality of life of patients and their partners, with many patients reporting a significant physical and psychological burden of disease as well as a substantial impact on their social and professional lives.
2. Dermatologists and dermatology APPs can play a significant role in managing patients with HS by recognizing the impact of HS on patients and implementing patient-centered treatment strategies that consider impact early in the course of disease.

# Managing HS: A Multimodal and Collaborative, Patient-Centered Approach

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Third in the series entitled *A Window of Opportunity in HS: Recognizing Progression, Understanding Impact, and Implementing Timely Management*, this article explores strategies important to the successful management of patients with hidradenitis suppurativa (HS). The role of dermatologists and dermatology advanced practice providers (APPs), the value of a multidisciplinary approach to care, and the effectiveness of multimodal treatment plans are discussed.

## Dermatology providers play an essential role in comprehensive care for HS

HS was once viewed as a disease without a home, but that is no longer the case. Prior to diagnosis, patients may consult providers they see on a routine basis, including providers in primary care and gynecology, or they may seek care for acute symptoms from the emergency room or urgent care clinics.[13,23,25] While HS may be diagnosed by any specialty, recent guidelines recommend that the diagnosis be confirmed by a dermatologist or a provider with experience treating HS.[40] The strongest predictor for receiving medical treatment for HS and for escalating treatment, when needed, is being under the care of a dermatologist.[65] Consequently, patients whose HS was primarily managed by a dermatologist were more likely to be satisfied or very satisfied with their treatment than patients who were managed by a nondermatology provider.[66]

## Patients with HS may benefit from an integrated multidisciplinary approach

HS is associated with a high comorbidity burden.[9] In fact, 8 of 10 patients with HS have ≥1 comorbid condition.[23] As a result, clinical guidelines advocate for comorbidity screening and, when possible, interdisciplinary care **(Figure 1)**.[40] Dermatologists and dermatology APPs may perform examinations for comorbid skin conditions and conduct a brief review of systems for extracutaneous comorbidities, but they also may direct patients to primary care physicians (PCPs) for additional recommended comorbidity screening.[20] When possible, providing referrals to other specialties, such as rheumatology or psychiatry, or comanaging with primary care or gynecology providers may benefit patients with HS.[20]



**Figure 1** AN INTEGRATED MULTIDISCIPLINARY APPROACH TO TREATING HS

The diagnosis of HS is usually made by a dermatologist who manages skin manifestations of HS, but healthcare professionals outside the dermatology specialty are involved in the ongoing management of comorbidities.

- Dermatology and rheumatology
- Gastroenterology and endocrinology
- Primary care and obstetrics/gynecology
- Infectious diseases
- Psychiatry, psychology, and other mental health specialties
- General and plastic surgery
- Nutrition
- Social work and support groups

**Guidelines recommend a multidisciplinary approach, especially when surgical intervention is considered.**

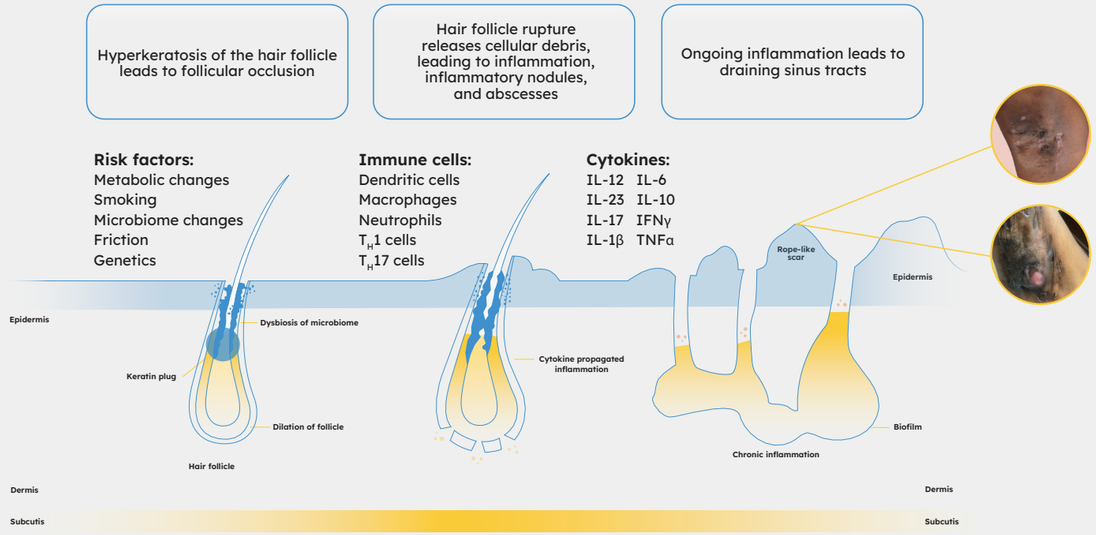
## HS is a chronic, inflammatory disease, often progressive with a complex pathophysiology

In recent years, a wealth of studies have established HS as a systemic inflammatory disease.[44] Endogenous factors in genetically predisposed patients as well as various exogenous factors, such as smoking, friction, metabolic changes, and the microbiome, contribute to follicular hyperkeratosis, which is now widely thought to be the primary event in HS.[67]

Follicular hyperkeratosis is believed to cause plugging and dilation of the hair follicle and subsequent follicle rupture **(Figure 2)**.[67] The rupture of the dilated follicle leads to the release of follicular content into the dermis, activating immune cells of the skin, which then increase the production and release of proinflammatory cytokines.[68] The continual activation of the immune system, as well as imbalance of fibrotic factors, results in ongoing inflammation, which may lead to scarring and the development of sinus tracts, also referred to as tunnels.[67] The cavities provide a habitat for bacteria, which may trigger secondary infection with associated drainage.[69] Severe disease resulting from chronic inflammation is associated with scarring and dyspigmentation.[67,70] In addition, emerging evidence suggests that increased levels of proinflammatory cytokines are present even in nonlesional skin in HS, further highlighting the inflammatory burden of HS.[71]

Due to the progressive nature and inflammatory profile of HS, the disease requires timely intervention. A recent study found an inverse correlation between therapeutic delay and the clinical response to treatment with a biologic, suggesting that early intervention with targeted therapy can help control inflammatory activity and help slow a destructive disease course.[42]

## Figure 2 HS HAS A COMPLEX PATHOPHYSIOLOGY




Top image of axilla of HS patient provided by Science Source. Bottom image of axilla of HS patient provided by Dr Moiin. Adapted from *Journal of the American Academy of Dermatology*, 82(5), Goldburg SR, Strober BE, Payette MJ. Hidradenitis suppurativa: epidemiology, clinical presentation, and pathogenesis, 1045-1058. © 2019, with permission from Elsevier.

*"Patients need to know from the outset that this is not a disease of infection, or of being dirty, or from glands or hormones. It is a disease of chronic inflammation. Most have never had proper treatment and are like runaway trains. Getting control of the disease quickly brings them back to the station, where they can start to heal."*

– Barry I. Resnik, MD

*"I explain to every new patient that HS is not just a skin disease and that it is a chronic, systemic inflammatory condition. I want patients to understand that it is not infectious or contagious, nor is it their fault. We discuss the role of the immune system and inflammation, which helps patients understand the need for systemic therapy targeting inflammation, treatment layering, and surgical management."*

– Tiffany Mayo, MD

## The management of HS is often multimodal

Outlined in clinical guidelines, the management of HS can include various treatments, including systemic and topical antibiotics, biologics, hormonal therapies, systemic immunosuppressants, surgical care, antimicrobial washes, and lifestyle modifications.[39,72,73] These various treatments affect the many processes that are thought to contribute to the pathogenesis of HS **(Figure 3)**. In many cases, management of HS is multimodal.[47]

*"I tell patients they have a disease with a 'medicines' deficiency. The minute we fill that deficiency, they're going to feel more human, and then, we'll use that medicine for as long as it continues to work. There is no expectation that using the medicine for a certain period will cure them. They need to understand that taking these medicines long term is not a life sentence, but a new life."*

– Barry I. Resnik, MD



## Immunoregulation is the cornerstone of care in HS

## Figure 3 TREATMENT OF HS IS OFTEN MULTIMODAL TO ADDRESS THE VARIOUS ETIOLOGIES UNDERLYING THIS DISEASE

**HS**

**METABOLIC DYSFUNCTION**
- Biguanides
- Dietary changes
- Weight loss

**HORMONES**
- Patient-specific oral contraceptives and other hormonal therapies

**DYSBIOSIS**
- Antiseptic washes
- Antibiotics

**IMMUNE DYSREGULATION (TARGETED)**
- Biologics

**IMMUNE DYSREGULATION (BROAD)**
- Corticosteroids
- Systemic immunomodulators

**FRICTION**
- Loose clothing
- Reduce friction
- Weight loss

**HYPERHIDROSIS**
- Botulinum toxin injections

**FOLLICULAR OCCLUSION**
- Retinoids
- Laser hair removal

Antibiotic monotherapy is often used as a first-line treatment.[72] Therapeutic effect of antibiotics in HS is likely due to their anti-inflammatory properties.[74] In addition, antibacterial therapies may prevent secondary colonization of lesions.[75]

The hormonal component of HS is supported by the effects of pregnancy and menstrual cycles on HS symptoms.[45,76] However, there is limited evidence to support the use of hormonal therapies for HS.[72] According to clinical guidelines, hormonal therapies may be suitable for mild to moderate disease or as an adjunct for severe disease. Patients who report an increase in flares around menses or who have features of comorbid polycystic ovarian syndrome may be most likely to benefit from hormonal therapy.[72]

Biologic therapy is recommended for moderate to severe HS.[72] Biologic therapies are thought to address the immunologic basis of HS and target cytokines that are dysregulated in the disease.[72] However, in a recent global survey, only 14% of patients with HS reported being treated with a biologic.[66] Strikingly, patients treated with a biologic reported higher treatment satisfaction compared with those treated with nonbiologic systemic medications.[66]

Surgical intervention also may be appropriate for patients who fail to respond to multiple medical therapies or for those with intractable, severe HS.[16] However, avoidance of surgery was reported as a priority treatment goal among patients.[54] Moreover, because surgery alone does not alter disease biology, management plans need to consider the trade-offs between extent of excision, surgical morbidity, and reducing the risk of future lesions.[77] Medical and surgical approaches can be complementary in HS management.

*"I often manage mild disease with topical antimicrobials, oral antibiotics, and hormonal medications, but I always remind the patient that HS is a chronic inflammatory condition that will likely require long-term systemic therapy to address their disease if/when it progresses. If a patient has not had any improvement in pain, abscesses, or drainage after 3 months, I switch therapies. If a patient partially responded, I try to stick with the regimen and add or layer additional therapies."*

– Tiffany Mayo, MD

## Considerations for selecting a management strategy

HS treatment guidelines recommend that the condition should be treated based on its individual, subjective impact and objective severity.[39] Hurley staging may be used to describe the progression and severity of HS.[37] However, several guidelines recommend incorporating patient-reported outcomes, such as the pain visual analog scale and Dermatology Life Quality Index (DLQI), into clinical assessments.[40] In clinical practice, several measures may be used simultaneously.[77] These measures may include the assessment of physical signs of HS, including lesion count, HS-specific assessments of quality of life, global assessments, and assessments of disease progression, including flare frequency and duration.[78] These measures were included in the core domain set for HS recommended by an international group of dermatologists specializing in HS, as well as patients with HS **(Figure 4)**.[78]

*"I recommend management that matches the disease severity and impact. The patient is involved in selecting a therapy they feel comfortable with. I give them my honest feedback on the likelihood that we will need to escalate when they select a conservative regimen, but I also give realistic expectations for more aggressive regimens."*

– Tiffany Mayo, MD

*"Hurley staging doesn't say anything about where they [patients] are going. It only says where they've been. Their responses to medical therapy and surgical treatment are the main indicators of therapy success or failure."*

– Barry I. Resnik, MD

### Figure 4

**CORE OUTCOME DOMAINS FOR HS PROPOSED BY HIDRADENITIS SUPPURATIVA CORE OUTCOMES SET INTERNATIONAL COLLABORATION (HISTORIC)**

**Pain**
Lesions of HS are typically described by patients as painful boils on the skin

**Physical Signs**
Anatomical location, surface area, total lesion count, inflammatory lesion count, number of abscesses, number of inflamed nodules, number of sinus tracts, number of fistulae

**HS-Specific Quality of Life**
Physical functioning, psychological functioning, psychosocial functioning, emotional well-being, ability to work or study

**Global Assessment**
Patient global, physician global

**Progression of Course**
Flare frequency and duration, time to recurrence

## Shared decision-making improves HS management

Shared decision-making, defined as a combination of communication of clinical evidence, provider experience, and patient values and preferences, has been shown to enhance patients' knowledge of HS and treatment options, reduce decisional conflict, and increase preparation for decision-making.[79]

Managing expectations is crucial during the early stages of care.[80] Consider counseling patients that there is no cure, improvement may be slow and studded with periods of disease worsening, and disease progression varies from patient to patient.[80] Treatment expectations may differ between patients and providers. In one study, pain reduction was among the 5 most important treatment attributes reported by patients. Improvements in skin appearance and mental health were also priorities for patients.[54] In contrast, HCPs prioritized treatment effectiveness, immunological control, and quality-of-life improvement.[54]

*"HS is a complex disease with multifactorial physiology and widespread impact. Ensuring that patient needs are adequately addressed is challenging and requires a counseling component regarding setting expectations. I emphasize that everything can't be addressed in one visit but that we will prioritize based on the patient's goals and work with medical colleagues for comprehensive care."*

– Tiffany Mayo, MD

## Conclusion

Although HS has no known cure, timely, effective management can improve patient outcomes. However, it is important to establish realistic treatment expectations early on and to consider patients' goals and preferences when presenting and ultimately choosing a management strategy for patients with HS.

## Key Takeaways

1. Clinical guidelines recommend that dermatologists confirm the HS diagnosis and, for most patients, a dermatology provider oversee their ongoing care.
2. Management of HS may be multimodal, and the various treatment options for HS help address the different factors that may contribute to disease pathogenesis; these treatments may have broad anti-inflammatory as well as targeted immunomodulatory properties.
3. The selection of an HS management strategy should consider objective disease severity, subjective impact of the disease on the patient, and the patient's values and preferences, which may differ from those of the provider.

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