

Hidradenitis Suppurativa Policy Brief

Delayed and Misdiagnosis of HS Impacts Patients Beyond Just Their Physical Health

What is Hidradenitis Suppurativa (HS)?

Hidradenitis Suppurativa (HS) is a chronic, stigmatizing, and disabling skin condition that affects approximately 1 – 4% of people in the United States, though the true prevalence is still yet to be confirmed, and disproportionately impacts women of color. HS manifests as painful abscesses under the skin and can occur anywhere hair follicles are present on a person's body.¹ Although it can present anywhere, HS is most commonly seen in the armpits, groin, buttocks, and breasts.^{2,3} These deeply seated lesions may develop into odorous pus-filled abscesses, indiscriminately bursting. Even with timely treatment, significant scarring often develops. The intense physical pain and social isolation due to symptoms may cause mental health comorbidities including depression, anxiety, substance use disorders, psychiatric disorders, sexual dysfunction, and increased risk of suicide.⁴

There is no cure for HS. Management of HS may include lifelong use of oral medications, injectable biologics, surgery, pain management, and specialized wound care.

Misdiagnosis Impacts on Treatment and Health Disparities in HS

Misdiagnoses for HS patients can include skin issues like acne, ingrown hairs, and boils to sexually transmitted diseases depending on where the abscesses present.⁵ Additionally, autoimmune diseases such as Crohn's disease present similarly and are often comorbid with HS which increases the possibility of misdiagnosis. In one study about 1% of Crohn's patients also presented with HS, and over 35% of HS patients also had Crohn's.⁶ The best way to get an accurate diagnosis is to see a dermatology specialist.⁷ Patients may be unaware they have HS for years due to a general lack of knowledge of the symptoms and the stigma surrounding the disease. Recent articles are shining a light on patients who have received no diagnosis or misdiagnosis for their symptoms while living with the disease for several years.⁸ Although the median age of HS onset is 21 years of age,⁹ recent data has shown that **only about 25% of patients are diagnosed before the age of 25.**¹⁰

The timing of a patient's diagnosis can compound treatment issues as many HS patients commonly receive at least one misdiagnosis before identifying their condition as HS, with over one-third of patients in one study reporting at least one misdiagnosis.¹¹

Studies have shown that **HS disproportionately affects individuals from underrepresented populations who are subject to significant healthcare disparities including women, young adults, and Black patients disproportionately.**² These disparities are further exacerbated for people of color who may be misdiagnosed or have a delayed diagnosis. On average, Black patients saw a diagnosis delay of 4.8 ± 7 years and Hispanic patients' diagnosis was delayed by 4.7 ± 5.8 years compared to a 3.2 ± 6.3 year delay for white patients.¹² Black and Hispanic patients were often observed to be in later stage of disease severity.¹³

Misdiagnosis and delayed diagnosis prevent timely access to effective treatments for HS, compounding the negative physical, mental, and emotional outcomes associated with HS. This may include scarring

and skin changes, physical distress as a result of lesion pain further exacerbated by infection that requires medical treatments, as well as an increase in anxiety and depressive disorders.¹⁴ **HS patients are twice to four times as likely to commit suicide than patients with other skin diseases.**¹⁵

Misdiagnosis and late diagnosis have created long term effects that impact not only the quality of life of HS patients but also the overall financial burden of the disease for patients and insurance providers. A study on the work habits and insurance coverage of HS patients from various socioeconomic backgrounds found that **patients who were diagnosed earlier in their disease progression missed less work, left their jobs less due to HS related comorbidities, and were less likely to incur additional care costs, regardless of disease stage at diagnosis.** Following a new diagnosis of HS, the study found that patients showed \$324 - \$1843 less annual income compared to a control group over five years.¹⁶

Policy Recommendations

- Request a revision of STEP therapy requirements for HS patients on a state-by-state and federal level but reforming formulary requirements.
- Request federal health agencies to develop HCP and public education toolkits to promote early intervention and diagnosis of HS.
 - Targeting agencies focused on minority health education will ensure that those populations will receive resources that empower them in discussions and HCPs can identify early warnings signs and symptoms of HS – inclusive of diverse skin tones to reduce health disparities
- Require payers/insurers to include HS-specific provisions in their policies to break down barriers to HS screening and necessary diagnostic tools to accurately identify HS.

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