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Demography, Incidence, Prevalence, and Comorbidities in Hidradenitis Suppurativa: Insights from a Large-Scale Database Analysis

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Abstract

Background and Aims: Hidradenitis suppurativa (HS) is a chronic inflammatory skin disease characterized by painful nodules, abscesses, and draining tunnels in intertriginous regions. Despite extensive research since its description in 1854, the global prevalence remains highly variable (0.053%-4.1%), with notable disparities across demographic groups. This study examines demographic patterns and prevalence trends of HS in the United States to inform targeted public health strategies and improve patient outcomes through early diagnosis and intervention.

Methods: This retrospective cohort study analyzed HS incidence, prevalence, and trends from January 1, 2014 to December 31, 2024, using a de-identified electronic health record database (TriNetX platform). The cohort included patients diagnosed with HS via ICD codes. Primary outcomes were incidence proportion, prevalence, and incidence rate. Secondary analyses stratified data by age, race, and ethnicity. Patients with incomplete demographic data or insufficient follow-up were excluded.

Results: Over the 10-year period, 455,430 HS patients were identified from a base population exceeding 211 million individuals. Incidence proportion increased from 0.07 per 1,000 in 2014 to 0.94 per 1,000 in 2024, with prevalence and incidence rates showing similar upward trends. The greatest increases were observed among younger age groups, American Indian/Alaska Native and Asian populations, and Hispanic or Latino individuals. African Americans represented 30.2% of HS cases, indicating a disproportionate disease burden relative to their population representation.

Conclusion: HS incidence and prevalence have increased significantly over the past decade, particularly among specific racial, ethnic, and age groups. These trends likely reflect improved disease recognition, enhanced diagnostic awareness, and expanded healthcare access following policy changes such as the Affordable Care Act. The rising disease burden underscores the need for innovative multidisciplinary treatment strategies and continued research into genetic, inflammatory, and metabolic factors to identify novel therapeutic targets and improve patient outcomes.

Keywords: Hidradenitis Suppurativa; Epidemiology; Incidence; Prevalence; Racial Disparities; Health Equity; Chronic Inflammatory Disease

Introduction

Hidradenitis suppurativa (HS) is a chronic, recurrent inflammatory skin disease characterized by tender, deep-seated nodules, abscesses, and draining sinus tracts predominantly affecting intertriginous areas including the axillary, inguinal, genitoanal, and inframammary regions [1]. The condition was first described in 1854 by French surgeon Aristide Verneuil in his seminal work "Etudes sur les tumeurs de la peau" (Studies on the tumors of the skin) [2]. Despite this early recognition, HS remains underdiagnosed and often mismanaged, contributing to significant patient morbidity and reduced quality of life.

Since Verneuil's initial description, substantial research has advanced our understanding of HS epidemiology and pathogenesis [3]. The global prevalence estimates vary considerably, ranging from 0.053% to 4.1%, with disease onset typically occurring between ages 18 and 29 [3, 5]. Epidemiological studies reveal notable sex-based and ethnic differences in disease prevalence and severity [3, 4]. Familial clustering suggests a genetic predisposition, and HS demonstrates strong associations with obesity, metabolic syndrome, and inflammatory bowel disease [4].

The pathogenesis of HS involves complex interactions between follicular occlusion, immune dysregulation, and chronic inflammation [1, 8]. The disease process encompasses both adaptive and innate immune mechanisms, with key pathogenic events including follicular occlusion, follicular dilation and rupture, and sustained chronic inflammation leading to sinus tract formation and scarring [3].

Understanding demographic and prevalence patterns of HS is essential for developing targeted public health interventions and improving patient outcomes. This study leverages a large-scale electronic health record database to characterize HS epidemiology in the United States over a 10-year period, with particular attention to demographic disparities and temporal trends.

Methods

This retrospective cohort study examined the incidence, prevalence, and temporal trends of HS over a 10-year period from January 1, 2014, to December 31, 2024. Data were extracted from a large, de-identified electronic health record (EHR) database accessed through the TriNetX research network platform. The study cohort included all patients with at least one documented HS diagnosis (ICD-9: 705.83; ICD-10: L73.2) during the study period. Patients with incomplete demographic information or insufficient follow-up data were excluded.

Primary outcomes included incidence proportion (new cases per 1,000 individuals), prevalence (total cases per 1,000 individuals), and incidence rate (new cases per person-day). Secondary analyses stratified these outcomes by age groups, race categories, and ethnicity. Descriptive statistics and temporal trend analyses were performed using the TriNetX analytics platform.

Results

Overall Temporal Trends in HS

During the 10-year study period, 455,430 patients with HS were identified from a base population exceeding 211 million individuals. All epidemiological measures demonstrated substantial upward trends throughout the study period. Incidence proportion increased more than 13-fold from 0.07 per 1,000 individuals in 2014 to 0.94 per 1,000 in 2024 (Figure 1). Prevalence showed parallel growth, rising from 0.38 per 1,000 to 2.03 per 1,000, reflecting both new diagnoses and accumulation of prevalent cases over time. Similarly, incidence rate exhibited consistent upward trajectory from 0.20×10^{-6} to 2.67×10^{-6} per person-day, confirming the rising disease burden when standardized for observation time.

Age-Stratified Disease Burden

Age-stratified analyses revealed distinct patterns across demographic groups (Figure 2). The most pronounced increases in incidence proportion occurred in younger age groups, challenging traditional understanding of HS as primarily adult-onset disease. For ages 0-9, incidence proportion increased dramatically from 0.01 per 1,000 in 2014 to 0.14 per 1,000 in 2024. The 10-19 age group showed even more substantial growth, with incidence rising from 0.05 to 0.68 per 1,000. Adults aged 20-29 and 30-39 years, representing the traditional peak age of HS onset, maintained consistently higher baseline rates throughout the study period, though their relative percentage increase was proportionally smaller than younger cohorts. Middle-aged groups (40-49 and 50-59 years) demonstrated moderate but sustained growth in disease burden, while elderly populations (60+ years) showed the smallest absolute increases.

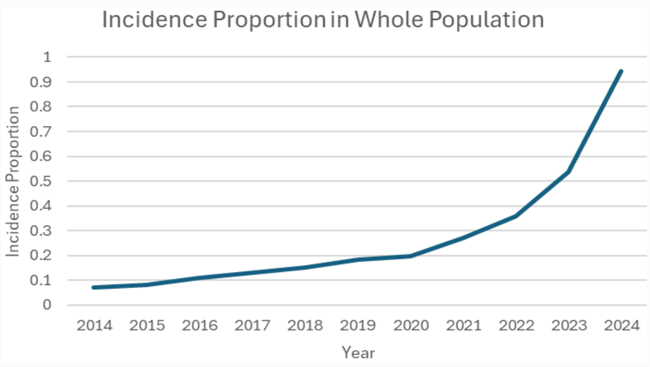

Figure 1: Incidence Proportion of HS Over Time (2014-2024).

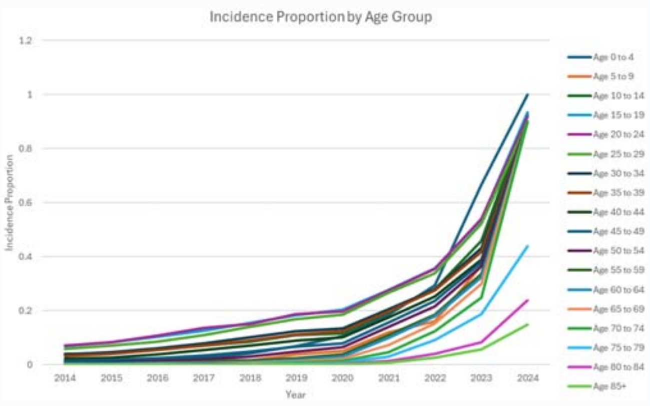

Figure 2: Incidence Proportion of HS by Age Group (2014-2024).

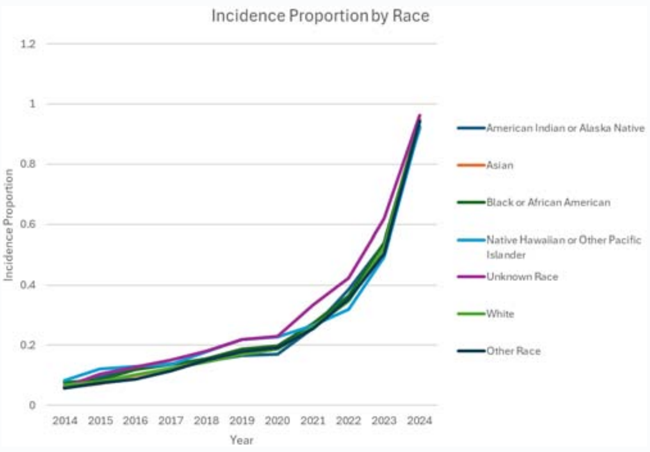

Figure 3: Incidence Proportion of HS by Race (2014-2024).

Racial and Ethnic Disparities in HS Burden

Racial stratification demonstrated significant disparities in disease burden and growth patterns (Figure 3). African American patients comprised 30.2% of all HS cases despite representing a smaller proportion of the general U.S. population, indicating substantial disproportionate disease burden. White patients constituted 51.2% of cases, reflecting the largest absolute number of affected individuals. The steepest relative increases in incidence proportion were observed among Asian populations (6.3% of cases) and American Indian/Alaska Native populations (0.6% of cases). Asian populations experienced particularly dramatic growth, with incidence proportion increasing from 0.02 per 1,000 in 2014 to 0.36 per 1,000 in 2024, representing an 18-fold increase. American Indian/Alaska Native populations showed similarly steep growth despite smaller absolute numbers, potentially reflecting improved access to care and disease recognition in historically underserved communities. Native Hawaiian/Pacific Islander populations (0.3% of cases) also demonstrated notable increases from a smaller baseline.

Ethnicity-based analysis revealed substantial increases across all groups. Hispanic or Latino individuals (15.6% of cases) experienced incidence proportion rising from 0.05 per 1,000 in 2014 to 0.58 per 1,000 in 2024. Non-Hispanic individuals (59.3% of cases) showed comparable growth from 0.08 to 1.06 per 1,000. A notable 25.1% of cases had unknown ethnicity data, which itself showed increasing trends over time, highlighting persistent gaps in demographic data collection that merit attention in future epidemiological studies and clinical documentation practices.

Discussion

This large-scale analysis of over 455,000 HS patients demonstrates a dramatic increase in disease incidence and prevalence across the United States over the past decade. The more than 13-fold increase in incidence proportion from 2014 to 2024 represents a substantial shift in the epidemiological landscape of this chronic inflammatory condition. While these trends may partially reflect true increases in disease occurrence, they likely predominantly represent improved disease recognition, enhanced diagnostic awareness among healthcare providers, and expanded access to healthcare services following major policy reforms such as the Affordable Care Act.

The disproportionate disease burden observed in African American populations, who comprise 30.2% of cases, aligns with existing literature documenting racial disparities in HS [9, 10]. Studies have demonstrated that African American patients not only experience higher disease prevalence but also present with more severe disease manifestations and face significantly longer diagnostic delays compared to other racial groups [9, 10]. These disparities likely reflect complex interactions between genetic susceptibility factors, environmental influences, socioeconomic barriers to healthcare access, and potential implicit biases in diagnostic practices. The observed increases in Asian and American Indian/Alaska Native populations are particularly noteworthy and may reflect previously underappreciated disease burden in these communities. For American Indian/Alaska Native populations specifically, well-documented barriers to specialty care access and clinical trial participation may have historically contributed to systematic underdiagnosis [11].

The substantial increases observed in pediatric populations, particularly among children and adolescents, challenge traditional understanding of HS as primarily an adult-onset disease. While the 20-29 age group has historically represented the peak incidence period [3], our data reveal disproportionate growth in younger populations. This trend may reflect improved recognition of early-onset disease among pediatricians and dermatologists, increased awareness of HS in younger populations, or potential shifts in disease epidemiology related to rising obesity rates and other modifiable risk factors in pediatric populations [5, 7]. Early disease recognition in children and adolescents is particularly crucial, as early-onset HS has been associated with more severe disease trajectories, greater psychosocial burden, and potentially different treatment response patterns compared to adult-onset disease [7].

The temporal correlation between increasing HS diagnoses and implementation of the Affordable Care Act (ACA) warrants careful consideration. The ACA's expansion of insurance coverage, particularly for previously uninsured populations and individuals with pre-existing conditions, may have substantially facilitated access to dermatologic care and specialist evaluation for individuals with previously undiagnosed or undertreated HS. This improved access could partially explain the observed increases across various demographic groups, particularly among historically underserved populations who may have previously faced significant financial and systemic barriers to specialty care.

The substantial proportion of cases with unknown ethnicity data (25.1%) highlights persistent challenges in demographic data collection and documentation within electronic health record systems. This significant data gap limits our ability to fully characterize ethnic disparities in HS burden and underscores the critical need for improved standardization and completeness of demographic data collection in clinical settings.

Limitations

This study has several important limitations that merit consideration. First, reliance on ICD diagnostic codes may result in case misclassification, as HS can be clinically misdiagnosed as other conditions (such as recurrent furunculosis or acne) or coded incorrectly in administrative databases. Second, our database captures only patients with documented healthcare encounters, potentially missing individuals with undiagnosed disease or those lacking access to medical care. Third, we cannot definitively distinguish between true increases in disease incidence and improved case detection and diagnosis. Fourth, the lack of disease severity data (such as Hurley staging) limits our ability to assess temporal trends in disease burden beyond simple case counts. Finally, the substantial proportion of cases with missing ethnicity data may introduce bias in ethnicity-stratified analyses.

Clinical and Public Health Implications

The rising incidence and prevalence of HS, coupled with persistent racial and ethnic disparities, necessitate a comprehensive, multifaceted public health response. Healthcare systems should prioritize HS education and training for primary care providers, pediatricians, and emergency medicine physicians to facilitate earlier diagnosis and appropriate referral, particularly in high-risk populations. Development of standardized diagnostic criteria and validated screening tools could substantially improve case detection and reduce the currently extensive diagnostic delays, which average 7-10 years from initial symptom onset to definitive diagnosis [6]. Given the substantial psychosocial burden of HS, which significantly impacts health-related quality of life across multiple domains [6], integrated multidisciplinary care models incorporating dermatology, surgery, mental health services, pain management, and nutritional counselling should be widely implemented. Targeted research into genetic susceptibility factors, inflammatory pathways, and metabolic contributors to HS, with particular focus on understanding the biological basis of observed racial and ethnic disparities, may yield novel therapeutic targets and enable development of personalized, precision medicine approaches to treatment.

Conclusion

This comprehensive analysis reveals a dramatic increase in HS incidence and prevalence over the past decade, with notable growth in specific demographic subgroups including younger individuals, Asian and American Indian/Alaska Native populations, and Hispanic/Latino communities. These trends likely reflect a combination of improved disease recognition, enhanced diagnostic awareness among healthcare providers, and expanded healthcare access following major policy reforms. The persistent overrepresentation of African American patients and emergence of previously underrecognized disease burden in other minority populations underscore the critical importance of health equity initiatives and culturally competent care delivery. Future research should focus on elucidating the genetic, immunologic, and environmental factors driving these demographic patterns while developing innovative therapeutic strategies to address the growing burden of this debilitating condition. Enhanced public awareness campaigns, improved diagnostic tools and algorithms, and comprehensive multidisciplinary treatment approaches are essential to improve outcomes for the expanding population of patients affected by HS.

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