Incidence of hidradenitis suppurativa in the United States: A sex- and age-adjusted population analysis

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Background: The true incidence of hidradenitis suppurativa (HS) is unknown.

Objective: To determine standardized incidence estimates for HS in the United States.

Methods: We used a retrospective cohort analysis, including incident HS cases identified using electronic health records data for a demographically heterogeneous population-based sample of >48 million unique patients across all 4 census regions. We calculated standardized 1- and 10-year cumulative incidences for the overall population and for sex-, age-, and race-specific groups.

Results: There were 5410 new HS diagnoses over a 1-year period, with an incidence of 11.4 (95% confidence interval [CI], 11.1-11.8) cases per 100,000 population. One-year incidence in women was 16.1 (95% CI, 15.5-16.6) per 100,000, more than twice that of men [6.8 (95% CI, 6.5-7.2) per 100,000; $P < .0001$]. Age group–specific incidence was highest among patients 18 to 29 years of age [22.0 (95% CI, 21.0-23.2) per 100,000]. Incidence among African Americans [30.6 (95% CI, 29.1-32.2) per 100,000] was >2.5 times that of whites [11.7 (95% CI, 11.3-12.2) per 100,000; $P < .0001$]. The average annual overall incidence over 10 years was 8.6 (95% CI, 8.6-8.7) per 100,000 population.

Limitations: The use of deidentified claims prevented validation for a larger case subset.

Conclusion: HS incidence has increased over the past decade and disproportionately involves women, young adults, and African Americans. (J Am Acad Dermatol 2017;77:118-22.)

Key words: African American; cumulative; epidemiology; hidradenitis suppurativa; incidence.

Hidradenitis suppurativa (HS) is a debilitating, painful chronic inflammatory disease whose inherent unpredictability, both with respect to course of disease and response to treatment, poses significant challenges for patients. With sparse epidemiologic data for HS, disease burden has not yet been established. We have previously reported an overall point prevalence of 0.1%, or 98 HS patients per 100,000 people in the United States (US). Group-specific HS prevalence was greatest among women, young adults, and black and biracial patients.[1] There are few adjusted population analyses reporting incidence rates for HS, and the true incidence of HS is unknown. The purpose of this study was to establish standardized 1- and 10-year cumulative incidences for HS in the

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Mr Lavian and Ms Lin contributed equally to the investigation and the article.
Funding sources: None.
Dr Garg has served as an advisor for AbbVie and received honoraria.
Accepted for publication February 5, 2017.

Reprints not available from the authors.
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Published online March 9, 2017.
0190-9622/$36.00

http://dx.doi.org/10.1016/j.jaad.2017.02.005

overall population and in specific demographic groups in the US.

METHODS

We performed a retrospective cohort analysis by querying a multiple health system data analytics and research platform.[2] Clinical information from electronic medical records, laboratories, practice management systems, and claims systems is matched using the single set of Unified Medical Language System ontologies to create longitudinal records for unique patients. The data were standardized and curated according to common controlled vocabularies and classifications systems including *International Classification of Diseases, 9th revision* (ICD-9), Systemized Nomenclature of Medicine—Clinical Terms, Logical Observation Identifiers Names and Codes, RxNorm, and the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition*.[3-5] At present, the database encompasses 27 participating integrated health care organizations. More than 48 million unique lives, representing approximately 15% of the population across all 4 census regions of the US, are captured. Patients with all types of insurance and those who are self-pay are represented. The earliest clinical observations in the data system are from 1999. The database is dynamic and performs periodic automatic updates. Population counts are reported by the database to the nearest 10, or represented as <10 if between 0 and 9, to prevent patient identification. In this analysis, all active nondeceased patients in the database at the time of our query (October 2016) were included in this study. The Systemized Nomenclature of Medicine—Clinical Terms term ''hidradenitis'' was used to identify incident cases. We randomly reviewed records of 150 patients with an ICD-9 code for HS (705.83) at our institution. Two trained medical students extracted clinical information documented by care providers in each chart. Two dermatologists (A.G. and A.A.) experienced in evaluating HS patients independently reconciled clinical information for each patient against a criterion checklist for the case definition adopted by the 2nd International Conference on Hidradenitis Suppurativa. Cases for which there was disagreement on HS diagnosis were reconciled by discussion between dermatologists. In this cohort, a single ICD-9 code for HS yielded a positive predictive value of 79.3% for diagnosis. This case identification has been shown previously to have a positive predictive value of 77%.[6]

CAPSULE SUMMARY

- Hidradenitis suppurativa incidence in the United States is poorly understood.
- Hidradenitis suppurativa incidence has increased over the past decade and disproportionately involves women, young adults, and African Americans.
- Physicians should be aware of the early signs and symptoms of hidradenitis suppurativa to facilitate early institution of therapy.

Statistical analysis

We calculated frequencies describing the demographic characteristics of patients with a new diagnosis of HS in the last 1 and 10 years. Sex- and age-specific cumulative incidences were calculated for 4 racial groups: white, African American, biracial (white and African American), and other (all others). Patients with existing HS before the relevant time period were subtracted from the denominator to reflect the true at-risk population. HS incidence over the last 10 years was calculated as an average annual incidence. In order to calculate sex- and age-specific HS incidences for the overall population, the number of new HS cases and total population size were collapsed across the 4 racial groups. Cumulative incidences were standardized using the direct method. The projected year 2000 US population was used as the standard population with 6 age groups: 0-17, 18-29, 30-39, 40-49, 50-59, and ≥60.[7] Estimates were age-adjusted for sex comparisons, sex-adjusted for age group comparisons, and sex- and age-adjusted for race comparisons. Crude and standardized incidence estimates were calculated based on patients with available race, sex, and age information. Confidence intervals for crude and standardized incidences were computed based on the Poisson distribution and gamma distribution,[8] respectively. Subgroup comparisons were carried out assuming the incidence ratio follows a lognormal distribution. All analyses were performed using SAS software (version 9.4; SAS Institute, Cary, NC).

RESULTS

There were 5410 new diagnoses of HS in the 1-year period beginning in October 2015. Women comprised 73% of new HS diagnoses. New diagnosis was most frequent among patients 18 to 29 years of age (28.6%), followed by patients 30 to 39 years of age (25.2%). More than half of new diagnoses