Diagnoses of Hidradenitis Suppurativa in the United States, 1979–2012

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Key Words

Hidradenitis suppurativa · Database analysis · Survey · Temporal trends · Epidemiology

Abstract

Hidradenitis suppurativa (HS) is rarely diagnosed in the United States. Delayed diagnosis is a significant problem in the management of HS. In the past decade, there has been an increase in HS research. To determine whether those efforts have led to an increase in diagnoses, an analysis of visits to physicians in the United States from 1979 to 2012 was performed, using National Center for Health Statistics (NCHS) databases. Patient visits to private physician offices, hospital outpatient departments, and emergency rooms were analyzed. An increase in visit rates at outpatient departments from 2003–2007 [6.3/100,000, 95% confidence interval (CI) 2.9–9.8] to 2008–2010 (30.4/100,000, 95% CI 13.9–46.9; $p = 0.017$) was found. Converting the data to estimated numbers of patients, a 7-fold increase in patients from 2002–2007 (2.5/100,000, 95% CI 1.4–3.6) to 2008–2010 (16.9/100,000, 95% CI 7.8–26.1; $p = 0.003$) was found. No significant increase in patient or patient visit rates were found when analyzing visits in the physician office setting or combined office

and hospital settings. Localization of increased diagnosis to outpatient departments may reflect the recent increase in clinical research. NCHS data can be useful in monitoring rates of HS diagnosis as an outcome of increased awareness of the disease.

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Introduction

Of the diseases of the skin appendages, hidradenitis suppurativa (HS) has a particularly negative effect on patients' quality of life [1]. HS is chronic, and the painful and often suppurative lesions characteristic of the disease can be disabling [2]. Misdiagnosis, inappropriate treatment, and fragmented care contribute to disease progression and debility [3]. An average of 7.2 years between symptom onset and HS diagnosis has been reported [4]. Diagnosis and access to experienced physicians are essential to effective disease management, but even with expert care, treatment of severe HS can be difficult [5]. There are no drugs approved for HS by the US Food and Drug Administration and no laboratory tests for its diagnosis. Database studies have shown that HS is rarely diagnosed in the United States

[6–9]; however, the true prevalence of HS, which includes undiagnosed and untreated populations, is unknown [10].

In the past decade, there has been growth in research directed towards HS. A PubMed search shows a steady increase from 21 papers published in 2004 to 116 published in 2014. The number that reported on clinical trials was 4 in 2004–2007, rising to 14 in 2011–2014. Beginning in 2008, 6 phase II trials of tumor necrosis factor inhibitors adalimumab [11, 12], infliximab [13], and etanercept [14–16] have been reported. New surgical techniques [17] and progress in photodynamic therapy [18] have been described. With emerging treatments and greater attention to the disease, it is of interest to know whether diagnoses are increasing.

In their study of medical records from 1968 to 2008 from the Rochester Epidemiology Project, Vazquez et al. [6] found a statistically significant increase in HS incidence rate from 5.7 per 100,000 in the 1990s to 9.6 per 100,000 from 2000 to 2008. Sung and Kimball [19] analyzed HS diagnoses in the patient population at Massachusetts General Hospital and found that the prevalence at that site increased from 0.11% in 2007 to 0.2% in 2011. To our knowledge, these studies, based on regional and institutional data, provide the only information on trends in the diagnosis of HS.

The work described here used databases of patient visits to physicians at ambulatory settings, compiled from surveys and made public by the National Center for Health Statistics (NCHS). Patients included those with private and public insurance and the uninsured. NCHS databases from 1979 to 2012 were analyzed, and the numbers and rates of HS diagnoses and the prevalence of patients with a diagnosis of HS were estimated. The significance of recent increases was determined by comparison to the historical data.

Methods

The National Ambulatory Medical Care Survey (NAMCS) and the National Hospital Ambulatory Medical Care Survey (NHAMCS) collect information on an annual basis from sampled patient-physician encounters, or visits, within the United States, and provide databases that can be used to produce national estimates of healthcare utilization. Detailed documentation for these surveys and databases is provided by the NCHS [20]. NAMCS data files are derived from patient record forms documenting visits by patients to private physician offices and clinics, and NHAMCS files contain data from visits to hospital outpatient departments (OPDs) and emergency departments (EDs). Previous research using these databases has shown that all 3 ambulatory settings are relevant to the treatment of patients with HS [8].

The first survey year in which International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis codes were used in NAMCS and NHAMCS was 1979. All publicly available files from that year forward were analyzed. For NAMCS, the files were from 1979–1981, 1985, 1989–2010, and 2012, and for NHAMCS, OPD and ED the files were from 1992–2010. These files comprised a total of 2,167,724 patient visit records. Each record has an associated sample weight that takes the multi-stage survey design into account and reflects the probability of selection and the provider and visit level [21]. Records of visits that included a diagnosis of HS (ICD-9-CM code 705.83) were selected using the maximum of 3 physician diagnoses listed within each record.

The estimated number of visits with HS diagnosis was calculated for each survey year using SPSS, version 21, software (IBM Corp., Somers, New York, N.Y., USA). The Complex Samples Module of SPSS was used to calculate the number of visits and the standard error (SE) for survey files from 2002 and later. For files from 1992 to 2001, SE was calculated from the formulas and coefficients provided in the survey documentation for each year. For earlier year data, tabular values in the documentation were fit to formulas and the coefficients thus obtained used to calculate SE.

NCHS criteria for statistical reliability were followed; estimates with relative SE of 30% or more or those based on fewer than 30 records ($n = 30$) were not considered reliable. Records from survey years were combined to produce reliable estimates of visits in office settings only (NAMCS data), in all settings (combined NAMCS and NHAMCS OPD and ED data), in hospitals only (NHAMCS OPD and ED), and in hospital OPDs only (NHAMCS OPD). The number of years that were combined in an analysis was minimized and depended on the visit settings included in that analysis. Only reliable estimates are reported.

The number of patients with diagnosis of HS was estimated using the methodology of Burt and Hing [21]. This methodology was applied to survey years 2002 to 2010, for which files for all 3 settings are available and which include in the records a required variable for the number of past visits to the same physician within the previous 12 months. The use of this method for converting from numbers of visits to numbers of patients with HS within a survey year has been described in detail previously [8].

Estimates of the number of patient visits and numbers of patients with diagnosis of HS were converted into the corresponding rates using annual intercensal population data for residents of the United States [22]. Estimates of the population in 1979 that excluded armed forces overseas were obtained by extrapolation from 1980–1981 data.

Rates across groups of combined years in a visit setting or settings were compared using 2-tailed *t* tests, with significance at 0.05 level. When more than 2 groups of years were compared, the Bonferroni inequality was used to determine the critical value for statistically significant differences based on the number of *t* tests performed.

Results

From 1979 to 2012, the most recent survey year, there were 515 records within the NAMCS and NHAMCS data files that included a physician diagnosis of HS. These re-

Table 1. Estimated average annual number of patient visits with a diagnosis of HS, at physician office or clinic setting (NAMCS) or at any setting including hospital OPDs and emergency rooms (combined NAMCS and NHAMCS)

Survey type	Survey years	Estimated average annual number of visits	SE	n
NAMCS only	1979–1981, 1985, 1989–1990	100,000	27,000	57
	1991–1995	140,000	40,000	47
	1996–2001	156,000	44,000	34
	2002–2007	164,000	35,000	41
	2008–2010, 2012	225,000	62,000	43
NAMCS and NHAMCS (OPD and ED)	1992–1995	172,000	46,000	92
	1996–1998	217,000	65,000	50
	1999–2002	191,000	53,000	90
	2003–2005	206,000	53,000	58
	2006–2008	225,000	56,000	78
	2009–2010	364,000	105,000	67
Estimates are rounded to the nearest thousand.				

cords represent 4,961,000 patient visits [95% confidence interval (CI) 3,988,000–5,934,000] at any of the ambulatory settings of physician office or clinic, hospital OPD, or ED. In the years for which there is only NAMCS data (2012 and prior to 1992) there were 80 records with HS diagnosis. From 1992 to 2010, for which NAMCS and NHAMCS data are available, there were 132, 212, and 91 records, respectively, for physician office, OPD, or ED visits with HS.

The average annual number of patient visits at a physician office that included a diagnosis of HS more than doubled from the survey years 1990 and earlier to 2008 and later (table 1). Average annual visits at all settings showed a similar increase from 1992 to 2010.

The age of patients diagnosed with HS in the data files ranged from under 1 to 79 years; however, 98.7% of all visits with HS diagnosis were with patients aged 10–69 years. Figure 1a shows the average annual visit rate at the physician office setting calculated as the ratio of visits with HS diagnosis to a reference at-risk population of all residents between the ages of 10 and 69 years from census data. An increase of about 70% is seen in comparing the 1979–1990 period (54.8 per 100,000, 95% CI 25.7–83.9) to 2008–2012 (93.5 per 100,000, 95% CI 43.1–143.9), but it does not reach the level of significance. For all settings combined (fig. 1b) and for hospital settings (OPD and ED) only (fig. 1c), the visit rate during the 2009–2010 pe-

riod is higher than for earlier years, but not significantly. However, for the analysis of OPD visits only (fig. 1d), the visit rate for most recent years (2008–2010, 30.4 per 100,000, 95% CI 13.9–46.9) is significantly higher than for preceding years (2003–2007, 6.3 per 100,000, 95% CI 2.9–9.8; $p = 0.017$).

Converting from numbers of visits with HS diagnosis to numbers of patients, a similar pattern is found. The average annual number of all patients at all settings (fig. 2a) was 46.8 per 100,000 (95% CI 25.6–68.0) from 2002 to 2006, 50.7 per 100,000 (95% CI 25.4–75.9) from 2007 to 2008, and 59.9 per 100,000 (95% CI 30.2–89.6) from 2009 to 2010. These increases were not significant. The number of patients at hospital OPD and ED settings (fig. 2b) increased with time, but also not significantly. When considering only the hospital OPD setting, there was a highly significant ($p = 0.003$), approximately 7-fold increase in patients from 2002–2007 (2.5 per 100,000, 95% CI 1.4–3.6) to 2008–2010 (16.9 per 100,000, 95% CI 7.8–26.1).

Discussion

The increase in the number of visits and of patients with diagnosis of HS seen in our analysis for the most recent survey years – from 2008 through 2010 – was specific to hospital OPDs. This finding may reflect the likelihood of clinical investigations being performed at hospitals and the availability of physicians having experience with those new therapies for HS. The increase in visits and patients coincides with a period of substantially increased activity in HS research as reported in the literature.

The average annual number of patients diagnosed with HS at all settings as determined here for the years 2007–2008, 50.7 per 100,000 person-years, is in close agreement with the 2007 prevalence rates (52.09, 95% CI 50.51–53.68 adjusted by sex or 51.02, 95% CI 48.59–53.46 adjusted by age, per 100,000 person-years) determined by Cosmatos et al. [7] using a large database of insurance claims from throughout the US.

The prevalence rates of HS that had been reported earlier by Sung and Kimball [19] for patients with HS diagnosis seen at an academic hospital, including those seen in the emergency room, are higher (110 per 100,000, 95% CI 100–130, in 2007 and 200 per 100,000, 95% CI 190–220, in 2011) than rates found here or by Cosmatos et al. [7] (fig. 2a). It is reasonable that the population of patients visiting a hospital with physicians having expertise in the treatment of HS will have a higher proportion of patients

Fig. 1. Estimated number of visits with HS diagnosis per 100,000 person-years, averaged over survey years. **a** Visits to physician private office or clinic (NAMCS data). **b** Visits to physicians at all ambulatory settings (NAMCS and NHAMCS OPD and ED data). **c** Visits to physicians at hospital OPDs and emergency rooms (NHAMCS OPD and ED data). **d** Visits to physicians at hospital OPDs only (NHAMCS OPD data). Error bars indicate SE.

with HS diagnosis than the general population of patients in the United States. The approximately 80% increase in Sung and Kimball's [19] prevalence between 2007 and 2011 is similar to the approximately 70% increase in patient rates in the hospital OPD and ED settings from 2007–2008 (13.7 per 100,000, 95% CI 6.3–21.2) to 2009–2010 (23.6 per 100,000, 95% CI 10.4–36.8; fig. 2b).

The finding of Vazquez et al. [6] of a near doubling in HS incidence from the 1990s to the years 2000–2008 cannot be directly compared to measures of prevalence of HS diagnosis. Prevalence of both visits and patients with HS diagnosis was relatively constant from the early 1990s through at least the mid 2000s in our data. Vazquez et al. [6] used population-based data from Olmsted County,

Minnesota. As the location of the Mayo Clinic, that county's residents may have access to physician experts and rates of diagnosis that differ from those of all residents of the US. Also, as the authors note, the demographic characteristics of Olmsted County differ from the United States as a whole.

Database studies of disease prevalence can be strongly dependent on the geographic region. When limiting the study to certain regions of the country, prevalence rates are seen to vary considerably from national rates. This may be due to demographic characteristics, referral bias, and differences in healthcare availability and utilization. The ambulatory healthcare survey databases NAMCS and NHAMCS are advantageous in their national scope

Fig. 2. Estimated number of patients with HS diagnosis per 100,000 person-years, averaged over survey years. **a** Patients visiting physicians at all ambulatory settings (NAMCS and NHAMCS OPD and ED data). **b** Patients visiting physicians at hospital OPDs and emergency rooms (NHAMCS OPD and ED data). **c** Patients visiting physicians at hospital OPDs only (NHAMCS OPD data). Error bars indicate SE.

and their continuity on an annual basis. NAMCS and NHAMCS provide data on patients with public health-care plans and the uninsured. Their limitations include numbers of sampled visits. Cosmatos et al. [7] found 7,927 insured patients with HS out of 15,054,519 members enrolled over a single year. Here, there were 515 survey records with HS diagnoses out of 2,167,724 total records over 3 decades. NAMCS and NHAMCS records are weighted on the basis of complex multi-stage survey design to yield estimates of numbers of visits. Standard errors of the estimates can be relatively large, so that it can be challenging to show statistical significance of results. However, it was possible to demonstrate a significant increase in visits and patients with HS diagnoses localized to the hospital OPD setting from 2008 to 2010 compared to previous years. This increase may reflect increased research efforts at those institutions and possibly greater knowledge of HS in the physician community resulting

from the increased body of literature in the field. Continued analysis of NCHS databases should provide important ongoing evidence of changing rates of diagnosis of HS as treatment options and awareness of the disease evolve.

Statement of Ethics

This study did not involve human subjects, and therefore was not submitted for ethical review.

Disclosure Statement

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