Prevalence of Hidradenitis Suppurativa (HS): A Population-Based Study in Olmsted County, Minnesota

Varun Shahi, B.S[1], **Ali Alikhan, M.D**[2], **Benjamin G. Vazquez, M.D**[2], **Amy L. Weaver, M.S**[3], and **Mark D. Davis, M.D**[2]

[1] Mayo Medical School, Mayo Clinic, Rochester, MN

[2] Department of Dermatology, Mayo Clinic, Rochester, MN

[3] Division of Biomedical Statistics and Informatics, Mayo Clinic, Rochester, MN

Abstract

BACKGROUND/AIMS—Hidradenitis suppurativa (HS) is a follicular occlusion disorder occurring in apocrine-rich regions of the skin. Estimates of the prevalence of this disorder have not been population-based. We sought to provide population-based information on the prevalence of HS in Olmsted County, Minnesota as of 1/1/2009.

METHODS—Rochester Epidemiology Project, a unique infrastructure that combines and makes accessible all medical records in Olmsted County since the 1960s, was used to collect population-based data on the prevalence of HS.

RESULTS—We identified 178 confirmed cases of HS that included 135 females and 43 males, and estimated the total sex- and age-adjusted prevalence in Olmsted County to be 127.8 per 100,000 or 0.13%. The total prevalence was significantly higher among women than men.

CONCLUSION—This study represents the first population-based investigation on the prevalence of HS. In this population-based cohort, HS was less prevalent than previous reports have suggested.

Keywords

Prevalence; Hidradenitis suppurativa; HS; population-based; follicular occlusion; acne inversa

Introduction

Hidradenitis Suppurativa (HS) is a follicular occlusion disorder occurring in apocrine-rich areas that often presents with tender, occasionally draining, papules and nodules with an onset early in puberty, occasionally leading to sinus tract formation.[1,2] Associations with other illnesses (e.g. inflammatory bowel disease) have been described.[3] Due to the involvement of many different sites, HS patients may see not only dermatologists, but also

Correspondence: Mark D. Davis, MD Department of Dermatology, Mayo Clinic 200 First St SW, Rochester, MN 55905. davis.mark2@mayo.edu.

general internists, colorectal surgeons, plastic surgeons, gastroenterologists and family physicians.[4] Until recently, population-based epidemiological data for HS had been lacking.[2] Vazquez et al. recently described the incidence of HS in Olmsted County, Minnesota over a four decade period, providing insight into the rate at which new cases occurred in their population, but did not examine prevalence of the disorder. Currently, prevalence estimates of HS vary significantly and are primarily restricted to self-reporting[5,6]; a recent prevalence study equating HS billing codes to an HS diagnosis did not verify patient notes to ensure validity.[7] To our knowledge, population-based prevalence data for HS have not been reported. The main purpose of this study is to provide population-based data on the prevalence of HS in Olmsted County, Minnesota.

Materials and Methods

Study Setting

The resources of the Rochester Epidemiology Project (REP), a unique infrastructure that combines and makes accessible all medical records from Olmsted County, Minnesota, beginning in the 1960s, was utilized to identify the cases.[8-10] The REP is a well-established and well-researched epidemiology resource; it is particularly effective because healthcare providers in Olmsted County use a single medical record system that allows an individual's medical information to be accessed from a centralized database.[11,12] REP is successful for many reasons: first, the population is relatively isolated (approximately 90-120 minutes from large metropolitan areas). For this reason virtually all of the health care delivered to the community is provided by a small number of health care providers. Second, all of these providers (with the exception of approximately 20 dental practices, 6 optometrists, and 3 mental health practitioners/psychologists) participate in the REP. For this reason, all conditions that come to medical attention at these providers (including all dermatologic diagnoses) are captured through this research infrastructure. Third, the data come directly from the health care providers – not from an insurance group, which would capture only part of the population.

Olmsted County is located in Southeastern Minnesota. It has a population of roughly 144,000 people, most of whom identify as White (83%) according to the 2010 Census.[13] Approval from both Mayo Clinic and Olmsted Medical Center institutional review boards was obtained prior to commencing the study.

Study Criteria

A prevalent HS cases was defined as a living Olmsted County resident as of 1/1/2009 with a prior diagnosis of HS between 1/1/1968 and 12/31/2008, who had not denied access to their medical records for research purposes. Cases were identified using HS-specific diagnosis codes including: Hospital Adaptation of the International Classification of Diseases (HICDA) codes ("hydradenitis, NOS," "hidradenitis, suppurative," "hydradenitis, suppurative," "hidradenitis, NOS, "hydradenitis, NOS," and "infection, sweat gland"), Berkson codes ("hydrosadenitis," "inflammation, sweat gland," "hydradenitis, hydro-adenitis, hidradenitis," and "hidradenitis, hidro-adenitis, hidrosadenitis"), and the International Classification of Disease-9 code "hidradenitis." Comprehensive chart review

was performed by two abstractors (BGV and AA) to determine if each case met criteria for HS diagnosis. Though not common, patients for whom a consensus could not be made were excluded from the study. A confirmed HS diagnosis was based on the presence of chronic (defined as being present for greater than 6 months in length from the onset of symptoms), bilateral, typical lesions present along the milk line or in perianal and/or perineal regions.[2] A third abstractor (VS) reviewed the medical records to confirm Olmsted County residency as of 1/1/2009.

Statistical Analysis

The point prevalence of HS in Olmsted County was calculated assuming the entire population of Olmsted County for 2009 was at risk. Age- and sex-specific denominator values for 2009 were derived using linear interpolation of the 2000 and 2010 census data for Olmsted County. Statistical tests and 95% confidence intervals (CI) were constructed assuming the number of prevalent HS cases follows a Poisson distribution. The prevalence estimates were age- and sex-adjusted to the population distribution of US whites in the year 2010. Statistical analysis was performed using the SAS version 9.2 software package (SAS Institute, Inc.; Cary, NC).

Results

Between 1968 and 2008, 1,263 patients who had received a diagnosis of HS were identified using the Rochester Epidemiology Project (REP) resources. Of these patients, 303 met the criteria for confirmed HS diagnosis. As of 1/1/2009, 20 of the 303 patients were deceased and105 were no longer residents of Olmsted County leaving 178 living Olmsted County residents with a diagnosis of HS prior to 1/1/2009. The 178 prevalent cases included 135 females and 43 males, of which 156 (87.6%) were White. The mean age as of 1/1/2009 was 45.2 years (SD, 15.6; range 16.2 – 81.4 years). The point prevalence per 100,000 as of 1/1/2009, stratified by age and sex, is summarized in Table I. The total sex- and age-adjusted prevalence in Olmsted County was 127.8 per 100,000 or 0.13% (95% CI, 108.9-146.8) The total prevalence was significantly higher among women than among men: 189.5 per 100,000 (95% CI, 157.4-221.7) and 65.5 per 100,000 (95% CI, 45.6-85.3), respectively (P<0.001). The highest prevalence was among women aged 20-29 years in 2009 (307.7 per 100,000). Among men, the highest prevalence was between 60-69 years (142.5 per 100,000). 60-69 years was also the age range with the highest overall prevalence (201.8 per 100,000). A sharp decline of prevalence is appreciated after the 60-69 age group for men, while this decline is not seen in women until after the 70-79 age group. Table II compares our reported prevalence against previous studies.

Discussion

We report a prevalence of 0.13% in this population-based study. The prevalence is significantly higher among women, particularly between the ages of 20-29 years. Cases had to meet strict criteria which were reconfirmed as part of the chart review.

Some studies have reported prevalence to be at about 1%,[5] while others have reported as high as 4%.[14] Such claims would propose HS to be a more widespread disease; however,

it is important to keep in mind that these were not population-based studies and many relied on self-reporting.[5,6] A recent study that relied on coding for diagnosis did not examine the patient records to ensure that the cases were likely HS and not some other skin condition occuring in apocrine gland-bearing areas.[7] This is important because many of the cases that were reviewed in our study were excluded because they did not meet the criteria described by Alikhan et al.[1] We found that many cases coded as HS were actually dermatitis, epidermal cysts, furuncles, and other skin conditions, upon examining the notes.

Our study has several important limitations that warrant consideration. Though we included patients with a diagnosis made before 1/1/2009, these patients may not have had active symptoms as of 1/1/2009 - thus prevalence may be overestimated. Furthermore, due to our strict inclusion criteria, mild or early cases may have been excluded, which could underestimate prevalence. However, it is important to note that many cases of HS are falsely diagnosed as such simply because the symptoms occur in anatomical areas common for HS. [2] Furthermore, detection bias may be likely since women are more likely to access healthcare and thus may explain the higher prevalence in women. Additionally, our results may have limited generalizability since we examined one predominantly White county in Southeast Minnesota. Nevertheless, to our understanding, this study represents the first population-based investigation on the prevalence of HS. Finally, the capture of cases is dependent on the patient approaching a health care provider, and recognition of the condition of interest. For that reason, the estimates reported in the paper may be an underestimate of the true burden of this condition in the community.

It is important to know the prevalence of HS since it gives us an idea of how many people in our population currently have this chronic illness. No prior population studies on the prevalence of HS have been done, thus this manuscript adds to the literature of HS. We purport that HS is a rare disease signficantly affecting more women than men. We recommend further population-based studies in other parts of the country and world to help further elucidate the epidemiology of this chronic, potentially debilitating disorder.

Acknowledgement

Abbreviation and Acronym List

HS   Hidradenitis suppurativa

REP   Rochester Epidemiology Project

CI   Confidence Interv

References

1. Alikhan A, Lynch PJ, Eisen DB. Hidradenitis suppurativa: A comprehensive review. J Am Acad Dermatol. 2009; 60:539–561. quiz 562-533. [PubMed: 19293006]

2. Vazquez BG, Alikhan A, Weaver AL, Wetter DA, Davis MD. Incidence of hidradenitis suppurativa and associated factors: A population-based study of olmsted county, minnesota. J Invest Dermatol. 2012

3. van der Zee HH, van der Woude CJ, Florencia EF, Prens EP. Hidradenitis suppurativa and inflammatory bowel disease: Are they associated? Results of a pilot study. Br J Dermatol. 2010; 162:195–197. [PubMed: 19681876]

4. Brown TJ, Rosen T, Orengo IF. Hidradenitis suppurativa. South Med J. 1998; 91:1107–1114. [PubMed: 9853721]

5. Revuz JE, Canoui-Poitrine F, Wolkenstein P, Viallette C, Gabison G, Pouget F, Poli F, Faye O, Roujeau JC, Bonnelye G, Grob JJ, Bastuji-Garin S. Prevalence and factors associated with hidradenitis suppurativa: Results from two case-control studies. J Am Acad Dermatol. 2008; 59:596–601. [PubMed: 18674845]

6. Esmann S, Dufour DN, Jemec GB. Questionnaire-based diagnosis of hidradenitis suppurativa: Specificity, sensitivity and positive predictive value of specific diagnostic questions. Br J Dermatol. 2010; 163:102–106. [PubMed: 20331444]

7. Cosmatos I, Matcho A, Weinstein R, Montgomery MO, Stang P. Analysis of patient claims data to determine the prevalence of hidradenitis suppurativa in the united states. J Am Acad Dermatol. 2012

8. Melton LJ 3rd. History of the rochester epidemiology project. Mayo Clinic proceedings Mayo Clinic. 1996; 71:266–274.

9. Rocca WA, Yawn BP, St Sauver JL, Grossardt BR, Melton LJ. History of the rochester epidemiology project: Half a century of medical records linkage in a us population. Mayo Clinic proceedings Mayo Clinic. 2012; 87:1202–1213.

10. St Sauver JL, Grossardt BR, Yawn BP, Melton LJ 3rd, Pankratz JJ, Brue SM, Rocca WA. Data resource profile: The rochester epidemiology project (rep) medical records-linkage system. International journal of epidemiology. 2012; 41:1614–1624. [PubMed: 23159830]

11. St Sauver JL, Grossardt BR, Leibson CL, Yawn BP, Melton LJ 3rd, Rocca WA. Generalizability of epidemiological findings and public health decisions: An illustration from the rochester epidemiology project. Mayo Clinic proceedings Mayo Clinic. 2012; 87:151–160.

12. St Sauver JL, Grossardt BR, Yawn BP, Melton LJ 3rd, Rocca WA. Use of a medical records linkage system to enumerate a dynamic population over time: The rochester epidemiology project. American journal of epidemiology. 2011; 173:1059–1068. [PubMed: 21430193]

13. Census BUS. Summary file—minnesaota [machine-readable data files]/ prepared by the. 2010 Census Demographic Profile. 2011

14. Jemec GB, Heidenheim M, Nielsen NH. The prevalence of hidradenitis suppurativa and its potential precursor lesions. J Am Acad Dermatol. 1996; 35:191–194. [PubMed: 8708018]

Table I

Point prevalence of Hidradenitis Suppurativa (HS) in Olmsted County, Minnesota as of January 1, 2009.

Age as of 1/1/2009 (years)	Total		Female		Male		Females vs. Males p-value
	No.	Prevalence per 100,000	No.	Prevalence per 100,000	No.	Prevalence per 100,000	
0-19	2	5.1 (0.6-18.4)	2	10.4 (1.3-37.7)	0	0	0.14
20-29	35	180.9 (126.0-251.5)	31	307.7 (209.1-436.7)	4	43.1 (11.7-110.4)	<0.001
30-39	39	197.9 (140.7-270.6)	27	276.8 (182.4-402.8)	12	120.6 (62.3-210.6)	0.013
40-49	35	174.3 (121.4-242.4)	28	276.1 (183.5-399.1)	7	70.4 (28.3-145.1)	<0.001
50-59	32	163.5 (111.8-230.8)	22	218.3 (136.8-330.4)	10	105.3 (50.5-193.7)	0.048
60-69	24	201.8 (129.3-300.2)	16	254.9 (145.7-413.9)	8	142.5 (61.5-280.7)	0.17
70-79	9	124.4 (56.9-236.2)	8	204.9 (88.4-403.7)	1	30.1 (0.8-167.5)	0.026
80+	2	38.4 (4.6-138.7)	1	30.2 (0.8-168.3)	1	52.7 (1.3-293.4)	0.66
Total	178	127.8 (95% CI, 108.9-146.8) [†]	135	189.5 (157.4-221.7)[‡]	43	65.5 (45.6-85.3) [‡]	<0.001

[†] Age- and sex-adjusted to the population structure of the 2010 US white population

[‡] Age-adjusted to the population structure of the 2010 US white population

Table II

Hidradenitis suppurativa. Estimated Prevalence of Present Study Compared to Previous Studies.

Authors	Year	Study Methodology	Year of Prevalence Estimate	Geographic Region	Prevalence estimate	Case Definition
Shahi et al. (present study)	2013	Retrospective analysis of a county population-based cohort, all ages	2009	Olmsted County, MN	0.13%	Subject was a resident of the county, still alive as of 1/1/2009, and met the following criteria between 1968 and 2008: A HS-specific diagnosis and presence of chronic (defined as being present for greater than 6 months in length from the onset of symptoms), bilateral, typical lesions present along the milk line or in perianal and/or perineal regions.
Cosmatos et al.	2012	Retrospective analysis of an insurance claims database, all ages (N=7927)	2007	United States	0.05%	Subject had a medical insurance claim that met the following criteria is 2007: 1 or more diagnoses with International Classification of Diseases, Ninth Revision, Clinical Modification code 705.83 for HS without a Current Procedural Terminology code for HS; 1 or more Current Procedural Terminology codes of 11450, 11451, 11462, 11463, 11470, or 11471 during 2007 without International Classification of Diseases, Ninth Revision, Clinical Modification code 705.83; or both.
Revuz et al.	2008	Survey mailed to a random sample of individuals, age 15 or older (N=6887)	2002	France	0.97%	Subject endorsed the following question:

Authors	Year	Study Methodology	Year of Prevalence Estimate	Geographic Region	Prevalence estimate	Case Definition
						'During the last 12 months did you repeatedly have big nodules or boils located in the armpits or groin, a disease called HS?'"
Jemec et al.	1996	Random sample of individuals invited for health examination, age 15-69 (N=599)	Not stated	Copenhagen County, Denmark	1% (None with active disease)	Subject endorsed the following question: "Have you had painful boils in the armpit or the groin during the last 12 months?"
		Consecutive series of patients attending a STD clinic (N=507)	1992-1994	Copenhagen County, Denmark	4.1%	Subject was identified as having presence of nodules or inflamed lesions compatible with the diagnosis of HS, or the presence of non-inflamed nodular lesions and comedones in the axillae or groin. Subjects who had "furuncles" elsewhere were not counted as cases so as to exclude staphylococcal infection.
Jemec et al.	1988	Randomly selected female hospital staff and patients referred for cosmetic excision of nevi or warts, age 17-59 (N=100)	Not stated	Not stated	4%	The diagnosis of HS was based on the clinical presentation, and a history of recurrent and chronic inflammation, recurring at the same place in the groin, under the arms, between the buttocks or on the breasts, the lesions suppurating, and unresponsive to normal treatment for boils, such as lancing.