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Prevalence and Characteristics of Hidradenitis Suppurativa in the Northern Finland Birth Cohort 1986 Study: A Cross-sectional Study of 2,775 Subjects

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A negative stigmatization related to hidradenitis suppurativa may prevent patients from seeking care. Thus, a large proportion of patients with hidradenitis suppurativa may be missing from studies based on hospital data. The aim of this study was to examine the prevalence and characteristics of hidradenitis suppurativa among 2,775 subjects in the Northern Finland Birth Cohort 1986 Study (NFBC1986), who were in their mid-thirties. The prevalence of hidradenitis suppurativa was 4.0% ($n = 110/2,775$), being higher in females (4.8%) than in males (2.5%) ($p < 0.01$). Of those defined as having hidradenitis suppurativa in this study, only 4 cases ($n = 4/110$, 3.6%) were found to have a hidradenitis suppurativa diagnosis either in the hospital (Care Register for Health Care) or in the primary healthcare data. In an adjusted model in logistic regression analyses, hidradenitis suppurativa was significantly associated with obesity (body mass index 30–55 kg/m²) (odds ratio 3.81, 95% confidence interval 2.80–5.22), female sex (1.99, 1.53–2.61) and smoking (1.56, 1.21–2.00). In addition, there was an association between hidradenitis suppurativa and self-reported poor overall health status. Hidradenitis suppurativa seems to be common at the population level and only a minority of these patients seek care for the condition.

SIGNIFICANCE

Hidradenitis suppurativa is a chronic inflammatory disease of hair follicles, characterized by painful oozing lesions. Due to negative stigmatization of the disease, patients with hidradenitis suppurativa do not easily seek help from physicians. This study examined the prevalence and characteristics of hidradenitis suppurativa in the Northern Finland Birth Cohort 1986 Study ($n = 2,775$). The study found that hidradenitis suppurativa affected 4.0% of the population. Only 4 cases of the study population were found to have diagnosis of hidradenitis suppurativa, either in hospital or in primary healthcare data. Hidradenitis suppurativa was associated with severe obesity, female sex, smoking and poor overall health status.

Hidradenitis suppurativa (HS) is a chronic, recurrent inflammatory disease of hair follicles, characterized by painful, subcutaneous lesions, most commonly located in the inguinal, axillary and anogenital regions (1). HS is one of the most distressing diseases in dermatology, with known impact on quality of life (2). The annual incidence of HS has not been widely studied, and has been reported to be 3.0-6.0/100,000 persons/year in Finland and Minnesota, US. (3, 4). Prevalence of HS varies between 0.1 and 4% (3, 4). HS affects women more frequently than men (female:male ratio 2:1–5:1) and the incidence is highest among young women (the highest reported prevalence is among those aged 20–39 years) (4–6). HS is associated with many comorbidities, such as cardiovascular diseases, inflammatory bowel disease, and depression (3, 7).

Although knowledge of HS and its associative comorbidities has increased in recent years there is little epidemiological data about the disease. In particular, there is a lack of epidemiological studies performed in the general population (8). Registry studies have large datasets as their strength; however, cases with mild symptoms may be missing. In addition, as the symptoms of HS are often embarrassing, patients may delay seeking help from a physician (9). Thus, the precise prevalence of HS remains unknown. The aim of this cross-sectional study was to examine the prevalence and characteristics of HS at the population level among 2,775 cases belonging to the Northern Finland Birth Cohort 1986 Study (NFBC1986) in their mid-thirties.

MATERIALS AND METHODS

The NFBC1986 Study is a population-based, longitudinal cohort study and research programme. Initially, the NFBC1986 included all 9,749 (9,432 live born) children in the 2 northernmost provinces of Finland whose expected days of birth fell between 1 July 1985, and 30 June 1986 (covering 99% of the children in that area) (10). The cohort subjects have been evaluated regularly since birth by means of health questionnaires and clinical examinations. In 2019 to 2020, at the age of 33–35 years, cohort members were invited

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to participate in a large follow-up study. In connection with that study the cohort members answered diverse health questionnaires regarding health and health-related factors.

Assessment of hidradenitis suppurativa

The presence of HS was based on the questionnaires. The study cases were asked: (*i*) "Have you had an outbreak of boils during the last 6 months in the following areas: axilla, groin, genitals, under the breast or abdomen, buttock or gluteal cleft?" and (*ii*) "How many boils have you had?"; the number of boils: (a) at least 2, (b) 3–5, (c) 6 or more. HS was defined if there was an affirmative answer to the first question combined with at least 2 boils (Appendix S1). These criteria are modified from validated criteria by Vinding et al. (11).

Assessment of other parameters

In the questionnaires, the study cases self-reported their weight, height, living habits (including smoking status, alcohol use, and physical activity) and their opinion about their current health status. Body mass index (BMI) was calculated as the ratio of weight to height squared (kg/m^2). Study participants were classified into 4 groups according to BMI and World Health Organization (WHO) criteria: underweight $<18.5 \, kg/m^2$; normal weight $18.5–25 \, kg/m^2$; overweight $25–30 \, kg/m^2$; and obese $30–55 \, kg/m^2$. To determine the use of alcohol, the Alcohol Use Disorders Identification Test was used (12). Smoking status was classified as (a) no smoking, (b) former smokers >6 months (quit smoking less than 6 months ago), (c) former smokers <6 months (quit smoking more than 6 months ago), and (d) current smoking. In addition, the history of other diseases (both somatic and psychiatric diseases) was asked as follows: "Do you currently have or have you had a below-mentioned doctor-diagnosed disease?" (Appendix S2). By the reported frequency of participation in physical and recreational activities during leisure time, the study cases were classified into 4 groups: Inactive (those who preferred to stay indoors reading or watching television and did not like sports much); Lightly active (those who exercised at least 4 h per week, e.g. by walking, cycling, fishing); Active (those who liked fitness training and had, e.g. running, swimming or skiing as a regular sport activity for at least 2 h per week); Very active (those who exercised several hours per week by running, orienteering or playing ball games). Socioeconomic status (SES) was determined by education: ((a) basic education or high school, (b) vocational education, (c) lower academic education, and (d) upper academic education), and by livelihood status: ((a) regular income, (b) social benefits such as unemployment benefit, (c) student allowance/sickness benefit, (d) no regular income).

Finnish Care Register of Health Care (CRHC)

Patient records (history of HS diagnosed in secondary or public primary care) were obtained from the Finnish Institute of Health and Welfare's statutory Care Register of Health Care (CRHC) and the AvoHILMO (Care Register for Primary Health Care), and diagnosis of HS was searched using the International Classification of Diseases (ICD) codes 7058C and L73.2. The CRHC contains inpatient data from all state-administered Finnish hospitals and from the largest private hospitals from 1987 onwards and outpatient visits from 1998 onwards. Outpatient visits in primary healthcare are included since 2011. Each record contains the identification numbers of the patient and hospital, primary and subsidiary diagnoses, and duration of hospital stay.

Statistical analyses

The characteristics of the study population are presented as proportions, means and medians. The two-sample *t*-test and Person's

χ^2 test were used to compare the distribution between HS groups. A logistic regression analysis was used to examine associations between HS and risk factors with crude (OR) and adjusted odds ratios (aOR) and 95% confidence intervals (95% CIs). The following potential confounding factors were adjusted for: sex, comorbidities, smoking, and overall health status. An additional adjustment was performed for BMI. The inverse probability weighting, utilizing propensity score methods were used, to generate sampling weights for survey respondents that accurately represent the eligible cohort, in multivariate logistics regression. Propensity score for participation was conducted using sex and education, socioeconomic and employment status as auxiliary variable. These methods were used to correct the participation bias, since there was over-representation of highly educated women in the cohort (personal communication with Nordström et al.). OR was used as a relative risk. The data were analysed using R software package version 4.1.0 (R Foundation for Statistical Computing, Vienna, Austria). A *p*-value <0.05 was considered statistically significant.

RESULTS

In connection with a 33- to 35-year follow-up study, health questionnaires were sent to $n=8,896$ study cases. Of these, $n=2,831$ responded to the questionnaires (31.8%); 62.9% of respondents were female. There was some missing data ($n=56$) and, thus, the final study population included $n=2,775$ cases.

The prevalence of HS was 4.0% ($n=110/2,775$), being higher in females (4.8%) than in males (2.5%) ($p<0.01$) (**Table I**). The majority of the patients ($n=90/110$, 81.8%) had had 3 or more boils during the previous 6 months. Of those defined as having HS in this study, 4 cases ($n=4/110$, 3.6%) were found to have a diagnosis of HS, either in hospital (CRHC) or in primary health-care data.

The most common localization of boils was genitals (53.6%), seen more commonly in females (61.2%) than males (28.0%) ($p<0.01$). In addition to the genital area, groins (57.6%) were a typical site of boils in females. In males, the buttocks were the most usual site (48.0%) of HS, followed by axilla (36.0%) and groins (36.0%).

There was more smoking (31.8%) and obesity (41.3%) among those with HS than among those without (24.3% and 16.1%, respectively) ($p<0.001$ and $p<0.05$, respectively). Study cases with HS also had more alcohol use and less physical activity compared with their controls, but the difference was not statistically significant. There was no statistical difference in SES between cases and controls (Table I).

The cases with HS reported their overall health to be significantly worse than the controls ($p<0.01$) and they more commonly reported both somatic and psychiatric comorbidities than did controls (**Table II** and **Fig. 1**). In logistic regression analyses (adjusted with comorbidities, BMI, sex, current health status (patient's own opinion) and smoking), subjects with obesity (BMI $30–55 \, kg/m^2$) had nearly 4-fold risk (OR 3.81, 95% CI 2.80–5.22) of having HS compared with controls. Correspondingly, female sex (OR 1.99, 95% CI 1.53–2.61) and smoking

Table I. Basic characteristics of the study population[a]

	HS (N = 110)	No HS (N = 2,665)	Total (N = 2,775)	p-value[b]
Sex, n (%)				0.002
Male	25 (22.7)	990 (37.1)	1,015 (36.6)	
Female	85 (77.3)	1,675 (62.9)	1,760 (63.4)	
How satisfied are you with your current situation in life in general? n (%)				0.002
Very satisfied	9 (8.3)	499 (18.9)	508 (18.4)	
Somewhat satisfied	63 (57.8)	1,608 (60.8)	1,671 (60.7)	
Somewhat dissatisfied	33 (30.3)	495 (18.7)	528 (19.2)	
Very dissatisfied	4 (3.7)	41 (1.5)	45 (1.6)	
Cannot say	0 (0.0%)	3 (0.1%)	3 (0.1)	
BMI, kg/m^2				< 0.001
Mean (SD)	29.5 (6.9)	25.9 (4.8)	26.1 (5.0)	
Median (Q1, Q3)	27.9 (24.0, 34.6)	25.0 (22.8, 28.0)	25.1 (22.8, 28.2)	
Min–Max	19.5–59.1	14.9–56.8	14.9–59.1	
BMI according to WHO criteria, n (%)				< 0.001
Underweight	0 (0.0)	32 (1.2)	32 (1.2)	
Normal weight	33 (30.3)	1,265 (47.8)	1,298 (47.1)	
Pre-obesity	31 (28.4)	924 (34.9)	955 (34.6)	
Obesity	45 (41.3)	427 (16.1)	472 (17.1)	
Alcohol use according to AUDIT, n (%)				0.360
Low-risk consumption (score 0–7)	75 (75.0)	1,787 (78.7)	1,862 (78.5)	
Hazardous or harmful alcohol consumption (score 8–13)	18 (18.0)	391 (17.2)	409 (17.2)	
Likelihood of alcohol dependence (scores 14–)	7 (7.0)	94 (4.1)	101 (4.3)	
Smoking[c], n (%)				0.006
No	27 (24.5)	949 (35.8)	976 (35.3)	
Former smoker > 6kk	37 (33.6)	936 (35.3)	973 (35.2)	
Former smoker < 6kk	11 (10.0)	124 (4.7)	135 (4.9)	
Current smoker	35 (31.8)	644 (24.3)	679 (24.6)	
Livelihood status, n (%)				0.967
Regular income	85 (77.3)	2,111 (79.2)	2,196 (79.1)	
Social benefits	10 (9.1)	218 (8.2)	228 (8.2)	
Study grants/nursing leave benefits	13 (11.8)	287 (10.8)	300 (10.8)	
No regular income	2 (1.8)	49 (1.8)	51 (1.8)	
Education, n (%)				0.247
Basic education or high school	15 (13.6)	229 (8.6)	244 (8.8)	
Vocational education	34 (30.9)	800 (30.2)	834 (30.2)	
Lower academic education	38 (34.5)	928 (35.0)	966 (35.0)	
Upper academic education	23 (20.9)	694 (26.2)	717 (26.0)	
Civilization, n (%)				0.474
Divorced/judicial separation/single	43 (39.1)	948 (35.7)	991 (35.9)	
Relationship	67 (60.9)	1,704 (64.3)	1,771 (64.1)	
Physical activity, n (%)				0.069
Inactive	32 (29.6)	551 (20.9)	583 (21.3)	
Lightly active	45 (41.7)	1,039 (39.4)	1,084 (39.5)	
Active	29 (26.9)	958 (36.4)	987 (36.0)	
Very active	2 (1.9)	86 (3.3)	88 (3.2)	

[a]There may be some missing data while all study cases did not answer to all questions. [b]Two sample *t*-test otherwise χ^2 test. [c]Smoking status: former smokers > 6 months (quit smoking less than 6 months ago), former smokers < 6 months (quit smoking more than 6 months ago).
HS: hidradenitis suppurativa: BMI: body mass index; SD: standard deviation; WHO: World Health Organization; AUDIT: Alcohol Use Disorders Identification Test.

(OR 1.56, 95% CI 1.21–2.00) increased the risk of HS nearly 2-fold compared with males and non-smokers. There was also a significant association between poor overall health status and HS (OR 2.47, 95% CI 1.21–2.00) (**Table III**).

DISCUSSION

This study was conducted to chart the prevalence rate of HS in a unique NFBC1986 Study. The prevalence of self-reported HS was 4.0%, which is higher than that reported in larger studies from the USA (0.1%, *n* = 48 million) (5), France (~1%, *n* = 6,887) (8) or Denmark (1.8%, *n* = 27,275) (13). However, the prevalence level in 2 small Danish studies by Jemec and co-workers correspond to ours (~4%) (14, 15). The variation in the prevalence between the current study and previous studies is probably due to the differences in study methodology and study groups. For example, the general US population study included only cases who had sought care in health systems or had been diagnosed with HS (5). The large Danish study, in turn, consisted of blood donors and, thus, the study sample is probably not directly comparable with the general population (13). There were also some heterogeneities in mean age between the studies (8), with ours including only adults in their mid-thirties. Since HS is reported to affect young adults especially (with a female predominance), resembling our study population, the relatively high prevalence in the current study is reasonable. Surprisingly, only very few (*n* = 4/110) of the subjects with HS in the current study were found to have a healthcare contact regarding HS or diagnosed HS, strengthening the hypothesis that stigmatization related to HS may prevent patients from seeking care.

Table II. Somatic and psychiatric comorbidities between those with hidradenitis suppurativa (HS) and controls

Comorbidities*	HS (N = 110) n (%)	NoHS (N = 2,665) n (%)	p-value
Cardiovascular diseases			0.933
No	99 (90.0)	2,391 (89.8)	
Yes	11 (10.0)	273 (10.2)	
Diabetes			0.008
No	105 (95.5)	2,627 (98.6)	
Yes	5 (4.5)	37 (1.4)	
Thyroid diseases			0.752
No	104 (94.5)	2,499 (93.8)	
Yes	6 (5.5)	165 (6.2)	
Gastrointestinal diseases			0.083
No	86 (78.2)	2,247 (84.3)	
True	24 (21.8)	417 (15.7)	
Neurological diseases			< 0.001
No	68 (61.8)	2,039 (76.5)	
Yes	42 (38.2)	625 (23.5)	
Malignancies			0.055
No	103 (93.6)	2,582 (96.9)	
Yes	7 (6.4)	82 (3.1)	
Psychiatric diseases			0.019
No	75 (68.2)	2,070 (77.7)	
Yes	35 (31.8)	594 (22.3)	
Apnoea			0.027
No	105 (95.5)	2,619 (98.3)	
Yes	5 (4.5)	45 (1.7)	
Asthma			0.071
No	90 (81.8)	2,335 (87.7)	
Yes	20 (18.2)	329 (12.3)	
Chronic obstructive pulmonary disease			0.463
No	105 (95.5)	2,577 (96.7)	
Yes	5 (4.5)	87 (3.3)	
Musculoskeletal disorders and rheumatic diseases			0.375
No	77 (70.0)	1,966 (73.8)	
Yes	33 (30.0)	698 (26.2)	

*The detailed list of comorbidities is shown in Appendix S1.

However, since the healthcare data in the current study is registry-based, we cannot exclude the possibility of misdiagnosed HS (i.e. regular boils/abscesses).

In this study, there was a female preponderance in HS (2-fold risk), corresponding to other studies reporting the female-to-male ratio to be as high as 5:1 (6). The exact mechanisms behind the sex difference in prevalence of HS is unknown, but sex hormones are thought to be involved in the pathophysiology; e.g. pregnancy and premenstrual flares are known to exacerbate the

symptoms of HS, whereas onset of HS is rare after menopause (16).

The association between obesity and HS is well known from previous studies and the current study finding is consistent with others (4, 13, 17). The mean BMI among HS cases in the current study was 29.5 kg/m^2 (overweight) and nearly half (41.3%) of the cases were obese (females significantly more often than males) (4, 13, 17). In a Danish study, the mean BMI among subjects with HS was 27.0 kg/m^2 (13), and in a US study, 32.6 kg/m^2 (4). Some studies have found over 75% of patients with HS to be obese (17). Obesity can activate HS in many ways; it contributes to an abnormal hormonal metabolic status, causes low-grade inflammation, and, via increased skin-to-skin contact, leads to increased friction, maceration and occlusion, which may result in follicular hyperkeratosis and plugging (17). In addition to obesity, smoking is an important environmental risk factor of HS (17). In the current study, the subjects with HS reported significantly more smoking than controls. Like obesity, smoking influences the structure of the skin (e.g. stimulates follicular hyperplasia and occlusion, modifies sweat gland activity) and produces inflammatory reactions (17, 18).

The subjects with HS in this study considered their overall health to be worse than the controls. The burden of HS is known to be high and parallel to many chronic diseases, such as rheumatoid diseases (21). Correspondingly in the other Finnish study (2) patients with HS (n = 92, patients in tertiary care, evaluated by the generic 15 D questionnaire) had significantly diminished health-related quality of life compared with the general population. It is notable that, in that study, the findings were independent of HS severity (2). HS may be a very embarrassing disease with serious consequences, and patients with HS, especially females, consider the burden of HS to be very high (22), and have also been reported to have an increased risk of suicide regardless of whether they have a previous psychiatric diagnosis (23).

Association of HS with multiple somatic and psychiatric diseases has been shown in several studies (3, 7). In line with these, the current study found higher prevalences of many diseases in our subjects with HS compared with controls. Nevertheless, the association between comorbidities and HS may be modified by other factors, such as sex, smoking and BMI, as seen in our analyses. In particular, BMI was a strong risk factor for HS, which was the reason we performed an additional adjustment for BMI. However, due to the rather small group size, more studies are needed to evaluate specific diseases more accurately.

The major strength of this study is that it is based on a large (nearly 3,000 subjects) birth cohort population. Studies such as this one offer important information about the more realistic
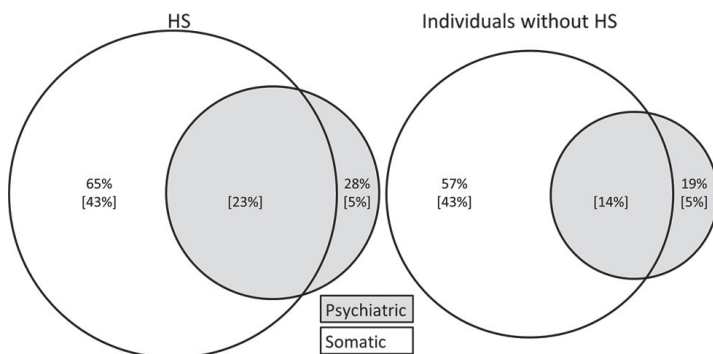

Fig. 1. Prevalence of psychiatric and somatic morbidity in patients with hidradenitis suppurativa (HS) and in those without HS. Values in brackets are the pure or comorbid prevalence of psychiatric or somatic disorders.

Table III. Association between hidradenitis suppurativa and risk factors

	Hidradenitis suppurativa		
	Crude odds ratio	Adjusted model 1[a]	Adjusted model 2[b]
Comorbidities			
Somatic or psychiatric comorbid	1.30 (0.84, 2.05) $p=0.252$	1.07 (0.80, 1.43) $p=0.65$	1.07 (0.80, 1.43) $p=0.67$
Somatic and psychiatric comorbid	2.14 (1.24, 3.64) $p=0.006$	1.24 (0.86, 1.79) $p=0.25$	1.12 (0.77, 1.62) $p=0.54$
Sex			
Female	2.01 (1.30, 3.22) $p=0.003$	1.92 (1.48, 2.50) $p=0.00001$	1.99 (1.53, 2.61) $p=0.0001$
How satisfied are you with your current situation in life in general?			
Satisfied	2.17 (1.13, 4.71) $p=0.032$	1.99 (1.26, 3.31) $p=0.01$	1.64 (1.03, 2.73) $p=0.05$
Somewhat satisfied	3.70 (1.83, 8.29) $p=0.001$	3.43 (2.11, 5.84) $p=0.0001$	2.12 (1.29, 3.66) $p=0.005$
Somewhat or very dissatisfied	5.04 (1.32, 16.17) $p=0.010$	3.76 (1.73, 7.97) $p=0.001$	2.47 (1.12, 5.29) $p=0.03$
Smoking status			
Current smoker or Former smoker <6 months	1.74 (1.17, 2.55) $p=0.006$	1.54 (1.20, 1.97) $p=0.001$	1.56 (1.21, 2.00) $p=0.001$
Body mass index[c]			
25–30 kg/m^2	1.32 (0.80, 2.17) $p=0.276$		1.38 (1.00, 1.92) $p=0.06$
30–55 kg/m^2	4.14 (2.62, 6.62) $p<0.001$		3.81 (2.80, 5.22) $p<0.001$

Logistic regression analyses: [a]Adjusted by comorbidities, sex, overall health status, smoking. [b]An additional adjustment for body mass index. [c]According to the World Health Organization (WHO) classification.

prevalence of HS, since they are not focused on selected patient groups: as seen in the current study, only a minority of the subjects with HS were found from the hospital/primary care register data. The participation rate in the study was satisfactory and comparable with the participation rates in other cross-sectional European health examination surveys (24, 25). In addition, due to the study design, we were able to evaluate comprehensively the basic characteristics and comorbidities of the patients with HS. As a limitation, even though the definition of HS in this study was based on the internationally accepted criteria (11), the possibility of misdiagnosis remains (due to self-reporting data) (26). However, self-reported diagnoses are, in turn, also stated to produce the highest estimates of HS prevalence (1). Nevertheless, since Koptyev et al. (26) have questioned the reliability of self-reporting in HS definition, we decided to slightly modify the criteria presented by Vinding and co-workers (11). Furthermore, we studied a narrow age cohort of Caucasian subjects, which may limit the generalization of the current results outside the birth cohort or to other age groups or ethnicities. Finally, not all invited cohort members participated in the study (there was an over-representation of highly educated women (personal communication with Nordström et al.), and, the rate of non-response must be regarded as sample bias. Furthermore, this may have led to some bias, both in the prevalence of HS and in the prevalence of comorbidities studied. However, the inverse probability weighting methods were used to correct this bias.

In conclusion, this study demonstrated a high prevalence of HS in this cohort population among subjects in their mid-thirties. HS was more common in females than in males and was associated with obesity and smoking. Subjects with HS were affected with a high burden of comorbidities and they considered their own health to be poor. Thus, the risk factors of HS in this unselected population seem to correspond to those in hospital register studies (7). It is noteworthy that only a few of the current study cases were registered in healthcare data because of HS, and thus, it is important to remember that HS cases are less likely to seek help for their disease.

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