

Hidradenitis Suppurativa in General Practice: A Pilot Study

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Abstract

Background: Hidradenitis suppurativa (HS) is a chronic debilitating skin disease with a diagnostic delay of 7 years. The general practitioner (GP) is often the first physician consulted by the HS patients, and often provide the initial treatment. Early diagnosis by GP is of major importance and may help to better control the course of the disease.

Aim: To describe GP's recognition and management of HS.

Methods: GPs in Belgium and Denmark were invited to complete a questionnaire constructed to describe general knowledge about HS.

Results: 103 Belgian and 51 Danish participated. Demographic characteristics were similar in both groups. Danish GPs estimated the disease to be more common. 0%/21.6% Belgian/Danish GPs seeing more than 20 patients with HS per week and conversely 28.2%/3.9% seeing no patients with HS per week. Belgian GPs were less likely to consider HS a chronic disease than the Danish GPs (41.7%/84.3%), and antibiotics were more commonly associated with HS by Danish GPs (31.4% versus 3.9%). Interestingly, Belgian and Danish GPs consider HS as an inflammatory (respectively 44.7% /58.8%) but also as an infectious disease (respectively 62.1%/ 64.7%).

Conclusions: The early diagnosis and a correct management is a crucial step to improve the prognosis of the disease. This pilot study has attempted to assess the general knowledge about HS of Belgian and Danish GPs. Important differences have appeared, suggesting a need for more information to facilitate the management of the patients. A multidisciplinary approach is suggested for the management of this often debilitating disease. Our pilot study evaluates for the first time the knowledge of GPs about Hidradenitis Suppurativa. Unfortunately the disease is often misdiagnosed and we have reported a mean diagnosis delay of 7 years. An early diagnosis by GPs could greatly improve the course and the management of the disease.

Introduction

Hidradenitis suppurativa (HS) is a chronic, inflammatory, recurrent, debilitating follicular skin disease that usually presents after puberty with painful, deep-seated, inflamed lesions in the apocrine gland-bearing areas of the body, most commonly the axillary, inguinal and anogenital region (Dessau definition, first International Conference on Hidradenitis suppurativa, March 30-April 1, 2006, Dessau, Germany).

The inflammatory nodules can progress to abscesses and mucopurulent discharge, with hypertrophic scarring and sinus tract formation in the late stages of the disease. HS is often associated with an impaired quality of life [1,2].

HS is histologically characterized by chronic follicular hyperkeratosis and its pathophysiology is not yet fully understood, but it likely includes an interaction between a complex genetic background and the effect of external factors [3].

HS has been considered to be a rare disorder but European studies based on population samples using validated questionnaires have

suggested a prevalence of 1%-2% in the general population and a peak prevalence of 4% (including mild cases) among young adults [4-8].

In the United States, registry studies have suggested a much lower rate of 0.05 to 0%, 13% [9,10]. Several factors can play a role in these apparently diverging estimates of the prevalence rate.

Different methodological approaches to the epidemiology undoubtedly play a role, but it may also be speculated that a lack of recognition of HS in the medical community, and reluctance by patients to present their stigmatizing disease for treatment play a role [11,12].

Little is known about the level of recognition of HS in the medical community. The present orphan status of the disease suggests that it is treated by many specialities, often with widely varying understanding of the diseases pathogenesis.

The diagnosis of HS does not require any test and is primarily made on the basis of its typical clinical presentation and has to fit with the criteria adopted by the 2nd International Conference on Hidradenitis suppurativa in San Francisco [13] (Table 1).

(1) Typical lesions, i.e., deep-seated painful nodules: 'blind boils' in early lesions; abscesses, draining sinus, bridged scars and 'tombstone' double-ended pseudo-comedones in secondary lesions
(2) Typical topography, i.e., axillae, groins, perineal and perianal region, buttocks, infra and inter mammary folds
(3) Chronicity and recurrences
All three criteria must be met for establishing the diagnosis

Table 1: Diagnostic criteria of hidradenitis suppurativa (adopted by the 2nd International Conference on Hidradenitis suppurativa, March 5, 2009, San Francisco, CA US)

The diagnosis has to be discussed when the recurrence of the lesions is more than 2 times/6 months [3].

The general practitioner (GP) is often the first physician consulted by the HS patients, and often provides the initial treatment. Only if initial treatment is not effective will the patients be referred for specialist treatment. Early diagnosis is of major importance and close collaboration between the GP and the specialists can lead to effective control and prevention of advanced disease.

The diagnosis of the disease is often delayed. Globally there appears to be an average delay of 7 years from onset of symptoms to diagnosis. It is speculated that a lack of recognition of the lesions by the physicians may play a role in this [11].

The aim of this study was therefore to evaluate the general awareness of HS among the GPs and comparing the awareness of the Belgian and Danish GPs.

Material and methods

GPs in Belgium and Denmark were invited to complete a 13 item questionnaire constructed to describe general knowledge about HS (diagnosis, pathophysiology, prevalence, and management). For each question, multiple options were given and the respondent had to choose the most suitable answer(s) according to his/her perception (Table 2).

Question 1
Sex : F / M
Question 2
Year of birth
Question 3
Year of end of medical studies
Question 4
Since how long are you working?
Question 5
How many patients do you have per week?
Question 6

<p>Mrs S., 49 years old has chronic abscesses since 10 years in the right and left axilla .The lesions are painful and suppurative.The lesions constituted with the years hypertrophic scars.Since 1 year, the patient has developed the same lesions in the groins.</p>
a. Furunculosis
b. Cutaneous tuberculosis
c. Lymphogranuloma venereum

d. Hidradenitis suppurativa
e. Abscesses
f. Bacterial infection
Question 7
Choose the word(s) associated with hidradenitis suppurativa :
a. Chronicity
b. Infection
c. Inflammation
d. Abscesses, furunculosis
e. Handicap
f. Antibiotics
g. Other
Question 8
What is the prevalence of hidradenitis suppurativa in the general population?
a. 1/100
b. 1/1000
c. 1/10000
d. 1/500
Question 9
How many patients suffering from hidradenitis suppurativa did you see in your career?
a. 0
b. 1-5
c. 5-10
d. 10-20
e. >20
Question 10
Do you manage hidradenitis suppurativa's patients yourself?
a. Yes
b. No
Question 11
Do you refer hidradenitis suppurativa's patients to other specialists?
a. Dermatologist
b. Surgeon
c. Internist/ Specialist in infectious disease
d. Other
Question 12

If you refer to the case in question 6, which treatment do you recommend?
a. Topical disinfection and daily bandages
b. Topical antibiotics
c. Systemic antibiotics
d. Surgical excision
e. Surgical incision
f. Immunosuppressive therapies (TNF blocking agents...)
g. Other:
Question 13
Do you think that the management of the hidradenitis suppurativa:
a. Is easy
b. Is complicated
c. Needs a multidisciplinary approach

Table 2: GPs questionnaire.

A paper format questionnaire was distributed to the Belgian GPs during the annual GPs’meeting organized at the Medical University of Brussels in 2011 (Union des Anciens Etudiants de l’Université libre de Bruxelles) and to the Danish GPs at the Regional Association of GPs meeting in Zealand, Denmark in 2014. In both instances, the questionnaires were collected at the end of the session.

The study was approved by the Ethics Committee of Erasme Hospital, Université Libre de Bruxelles (Reference number : B406.2011.118.56). Questionnaire studies of physicians’ knowledge do not require ethical committee approval in Denmark.

Statistical analysis

Data were analyzed using IBM® SPSS® Statistics software, version 22 for Windows. Data are shown as means with standard deviation (SD), medians and interquartile ranges (IQ), or numbers and percentages. Differences between groups of general practitioner (Belgian vs Danish) in distribution of variables were assessed using Student’s t-test, Mann-Whitney test, chi-square test or Fisher’s exact test as appropriate. For continuous variables, normality assumption checking was performed by inspection of residual and normal plots. All reported p-values are two-sided and a p-value of less than 0.05 was considered to indicate statistical significance.

Results

The demographic characteristics of the participants are summarized in (Table 3.1).

General practitioner	Belgian	Danish	p-value
Number of participants	103	51	
Sex, female, n (%)	47 (45.6)	20 (39.2)	0.45
Age, years, mean ± sd	56 ± 11	55 ± 7	0.62

Years since medical degree, median [25%-75%]	31 [23-37]	23 [19-32]	0.005
Years of practice, median [25%-75%]	28 [19-34]	16 [11-24]	<0.001
Number of patients/week, median [25%-75%]	100 [70-120]	100 [90-120]	0.12

Table 3.1: Demographic characteristics.

In total, 103 Belgian GPs (56 men (54.4%) and 47 women (45.6%)) and 51 Danish GPs (31 men (61%) and 20 women (39%)) participated in the study. The median age of the participants was similar in both groups. The median of total patients seen by GPs per week did not differ significantly between the groups.

A significant difference between the Belgian and the Danish GPs was observed concerning the number years of practice with respectively 28, (19years to 34 years) versus 16 (11-24 years) , p-value <0.001.

Recognition of HS

Based on the history and pictures of a clinical case, 86.4% of the Belgian and 84.3% of the Danish GPs diagnosed correctly the disease.

Significant differences were observed between the groups with fewer Belgian GPs considering HS a chronic disease (41.7% versus 84.3%) and antibiotics were less frequently associated to HS by the Belgian GPs (3.9% versus 31.4%). The correct prevalence of the disease was well estimated by 6.8% of the Belgian versus 21.6% of the Danish GPs.

Differences in the number of HS patients seen per week were also found, with 28.2% of the Belgian and 3.9% of the Danish GPs seeing 0 (no patients) and conversely 0 (none) of the Belgian GPs and 21.6% of the Danish GPs seeing more than 20 patients per week.

Belgian and Danish GPs consider HS as an inflammatory (respectively 44.7% versus 58.8%) but also as an infectious disease (respectively 62.1% versus 64.7%).

Finally, 34.4% of the Belgian and 69.4% of the Danish GPs managed the HS patients themselves.

Participants' responses are summarized in Table 3.2.

General practitioner	Belgian	Danish	p-value
1. Correct diagnosis of hidradenitis suppurativa	89 (86.4)	43 (84.3)	0.73
2. Characterization of the disease			
2.1 Chronicity	43 (41.7)	43 (84.3)	<0.001
2.2 Infection	46 (44.7)	30 (58.8)	0.1
2.3 Inflammation	64 (62.1)	33 (64.7)	0.76
2.4 Abscess/furunculosis	54 (52.4)	38 (74.5)	0.009
2.5 Handicap	29 (28.2)	15 (29.4)	0.87
2.6 Antibiotics	4 (3.9)	16 (31.4)	<0.001
3. Correct prevalence if the disease	7 (6.8)	11 (21.6)	0.007
4. Number of hidradenitis suppurativa patients/week			
4.1 0	29 (28.2)	2 (3.9)	<0.001
4.2 1-5	63 (61.2)	16 (31.4)	<0.001
4.3 5-10	4 (3.9)	15 (29.4)	<0.001
4.4 10-20	7 (6.8)	8 (15.7)	0.09
4.5 > 20	0 (0.0)	11 (21.6)	<0.001
5. Management of the HS patients by themselves	35 (34.0)	34 (69.4)	<0.001
6. Refer to a specialist			
6.1 dermatologist	86 (83.5)	40 (78.4)	0.44
6.2 surgeon	49 (47.6)	19 (37.3)	0.22
6.3 internist	7 (6.8)	0 (0.0)	0.1
6.4 Other	3 (2.9)	0 (0.0)	0.55
7. Therapeutical options			
7.1 Disinfection	68 (66.0)	7 (13.7)	<0.001
7.2 Topical antibiotics	18 (17.5)	2 (3.9)	0.021
7.3 Systemic antibiotics	62 (60.2)	33 (64.7)	0.59
7.4 Excision	38 (36.9)	24 (47.1)	0.23
7.5 Incision	20 (19.4)	8 (16.0)	0.61
7.6 Immunosuppressive therapy	8 (7.8)	2 (3.9)	0.5
8. Management of the disease			
8.1 easy	6 (5.8)	3 (5.9)	0.99
8.2 complicated	61 (59.2)	30 (58.8)	0.96
8.3 require multidisciplinary approach	50 (48.5)	20 (39.2)	0.27

Data are expressed as n(%)

Table 3.2: How is HS perceived among the Belgian and Danish general practitioners.

Discussion

HS is a chronic inflammatory debilitating skin disease and is one of the most distressing conditions observed in dermatology [14-16]. Nevertheless, patients experience a significant delay in diagnosis. We have therefore assessed the level of recognition and self-reported handling of HS by GPs who are often the first physicians to see HS patients in Belgium and Denmark. The data suggests that the disease is well recognized, with an 80% recognition rate in both countries. The data are self-reported and recognition was based on a constructed case and photographs, and it may be speculated that a different case-construction or a more ambiguous case would have changed the recognition rate. The clarity of the case suggests that the reported recognition rate should be regarded as the maximum rate for the respondents.

The diagnosis of HS is primarily clinical, and the key elements required to diagnose HS are the presence of typical and recurrent lesions located in typical skin areas (Table 1). HS is a complex disease with various phenotypic expressions and the diagnosis could be easily missed or confused with common infectious skin diseases [1]. Indeed, numerous elements like the common use of antibiotics in HS and the suggested hypothesis of an altered innate and adaptive immunity for its pathogenesis may reinforce the confusion with a skin infection [17]. Interestingly, HS is often classified in the skin bacterial infection chapter of some handbooks [18]. As potential first line medical care provider, the GP has to be able to recognize the clinical features of the disease and consider the diagnosis in patient with a chronic medical history of painful inflammatory nodules or abscesses with or without discharge. The chronicity of the disease was recognized in both countries, with 84.3% of the Danish and 41.7% Belgian GPs describing HS as a chronic disease. In our study, Belgian and Danish GPs consider HS as an inflammatory (respectively 44.7% versus 58.8%) but also as an infectious disease (respectively 62.1% versus 64.7%) and both propose systemic antibiotics as a primary therapeutic option to manage the disease, but although they also consider HS to be an inflammatory disorder only 7.8% of the Belgian and 3.9% of the Danish consider immunosuppressive therapy. A flare of the disease is frequently characterized by painful inflammatory nodules, abscesses and/or discharge. Based on our experience, antibiotics and/or incision are often proposed by general physicians with the hypothesis of a bacterial infection. We observed in our pilot study that the Belgian GPs propose more frequently incisions than Danish GPs (20% versus 8%).

HS is a complex and heterogeneous disease and its treatment remains a major challenge in general practice. In our work, Belgian GPs less frequently manage the HS patients themselves (34, 4% versus 69, 4% respectively). Frequently considered as gate-keepers to specialized health-care providers, a dynamic interplay between GPs and specialist is therefore suggested for the management of HS. GPs could play a key role in the early diagnosis and follow-up of the HS patients and will undoubtedly always be the link between the patient and the specialist.

The strength of our work is that it is the first pilot study evaluating the general knowledge of GPs. The study was conducted among the Belgian and Danish GPs where the highest prevalence of HS has been

reported in Denmark. We are planning to continue and include many other countries.

The weakness of our exploratory study is the paper format of the questionnaire, the sample size and the sampling procedure. The paper format did not allow the data to be divulged successively, i.e. Participants could turn to the last pages of the questionnaire where they could find the words "Hidradenitis suppurativa". Participants were instructed to fill in the questionnaire consecutively, but not all may have done so and it is unknown to what extent this may have influenced the answers. An electronic version may therefore be preferable in future studies. The sampling was done based on available samples at meetings and therefore suffers from potential bias and limitations of size. The meetings were, however, not related to the subject matter (skin disease).

Conclusions

The early diagnosis and a correct management is a crucial step to improve the prognosis of the disease. GPs are often the first physicians visited by the HS patients. This pilot study has attempted to assess for the first time the general knowledge about HS of Belgian and Danish GPs. Important differences have appeared that may derive from the number of patients seen by each. GP's awareness is still limited and may play a role in the significant delay experienced by HS patients. A multidisciplinary approach is highly recommended for the management of this often debilitating disease.

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