The journey of patients with hidradenitis suppurativa in Denmark and Norway: Real-world data from the HISREG registry

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Objective

To analyse the time from first hidradenitis suppurativa (HS) symptom to first dermatologist visit and the family history in patients with HS, using real-world data from the HISREG registry in Norway and Denmark.

Introduction

- A significant delay in diagnosis of 7–10 years from first symptom is observed globally for HS, a chronic, inflammatory skin disease.[1,2]
- A positive family history of HS occurs in approximately a third of patients.[3]
- Family history of HS may be a risk factor of HS, therefore knowledge of HS family history could aid reductions in diagnosis delays.[4]
- Dermatologists are more likely to diagnose HS;[2] thus early referral to dermatologists and patient awareness of the importance of early diagnosis is crucial.

Methods

- A secondary data analysis was conducted using data from adult patients diagnosed with HS (by a dermatologist) who enrolled in the HISREG registry from 2010–2022 and received ongoing treatment for HS.[5]
- Patient characteristics, median age at first HS symptom (first lesion/abscess as reported by patient), median time to first general practitioner (GP) and dermatologist visits, as well as family history of HS, were assessed in the HISREG registry overall, and separately for Denmark and Norway. All data were analysed using descriptive statistics.
- Data collection in Denmark did not include the relationships between family members with HS and data collection on family members with HS was only included in a sub-cohort in Norway from 2019 onwards.

Results

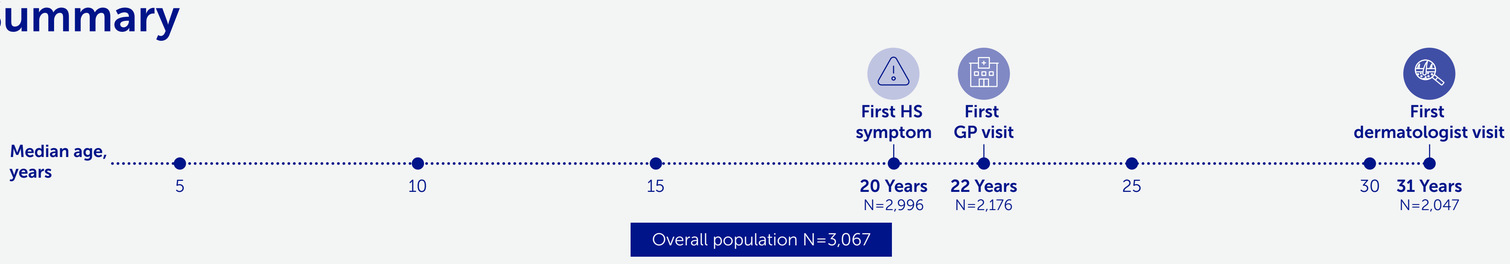
- In total, 3,067 adult patients with HS enrolled in the HISREG registry were included in this analysis (Norway: n=2,509; Denmark: n=558).
- Of the HS patient population, 76.4% (n=2,342) were female while 23.5% (n=721) were male (**Table 1**).
- Mean age at enrolment was 40.5 years (**Table 1**).
- The proportion of patients presented with Hurley Stage I, II and III were: 18.2% (n=557), 69.0% (n=2,115), and 11.5% (n=352), respectively (**Table 1**).
- The median age at first HS symptom was 20.0 years, with 38.3% (n=1,174) of patients aged <18 years at time of their first symptom. The median age at first GP visit was 22.0 years, with a 2-year delay from first symptom to first GP visit. The median age at first dermatologist visit was 31.0 years, resulting in an 11-year delay from first symptom to first dermatologist visit and a 9-year delay from first GP visit to first dermatologist visit (**Figure 1**).
- Overall, women presented with first symptoms, first GP and first dermatologist visits at a younger mean (SD) age (21.8 [9.8], 25.0 [11.0] and 32.8 [13.0] years) vs men (24.7 [11.8], 27.7 [12.9] and 35.0 [14.4] years); however, time between first symptom, first GP and first dermatologist visits was similar between women and men (**Figure 1**).
- In the total cohort, of those with available data, 45.7% (n=415) of patients reported a family history of HS. Of patients with available data, 45.3% (n=149) of patients in Denmark and 45.9% (n=266) of patients in a sub-cohort in Norway reported having a family member with HS (**Figure 2A–D**).
- In both countries, the frequency of a reported positive family history of HS was higher in women (n=335; 47.7%) vs men (n=79; 38.7%) (**Figure 2A**, **2C**).
- In the Norway sub-cohort that included data collection on family members with HS (N=266), most patients reported the family member as mother (21.8%; n=58) or multiple members (28.2%; n=75) (**Figure 2A**). Men and patients with Hurley Stage III were most likely to report having siblings with HS (28.3%, n=13 and 25.5%, n=12) (**Figure 2A**, **2B**).

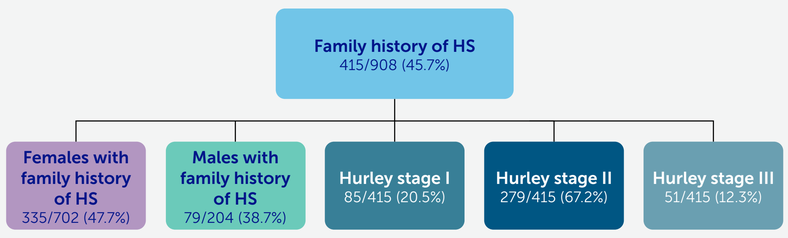
Conclusions

In Norway and Denmark, considerable delays of 11 years from first symptom to first dermatologist visit, and 9 years from first GP visit to first dermatologist visit were observed.

The high prevalence of a positive family history of hidradenitis suppurativa observed in the registry underscores the importance of family medical history as a valuable factor in aiding early disease diagnosis, especially in women.

Summary





N numbers represent the total number of patients in that subgroup (Female, Male, Hurley stage I, II or III) with available data. n values present those within each subgroup who have a positive family history of HS.

This real-world evidence study from Norway and Denmark highlights **considerable delays** between **symptom onset** and **first visit to a dermatologist**.

This study also highlights that HS is **more common** in the **female population** and that around **45%** of patients with HS display a **family history** of disease.

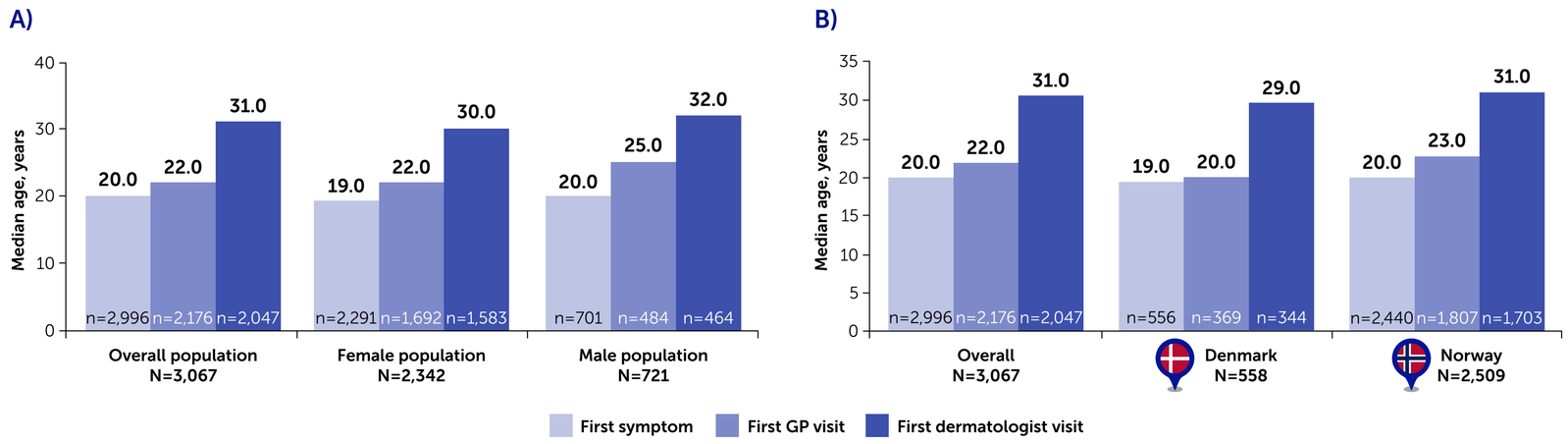
Knowledge of the **family history** and **earlier referral** to a dermatologist could **reduce delays in diagnosis** and HS-specific treatment.

Table 1 Characteristics of HISREG population

	Total cohort N=3,067	Denmark N=558	Norway N=2,509
n (%)			
Female	2,342 (76.4%)	421 (75.4%)	1,921 (76.6%)
Male	721 (23.5%)	135 (24.2%)	586 (23.4%)
Mean age at enrolment, years, SD	40.5, 12.6	40.6, 12.4	40.5, 12.6
Hurley stage I	557 (18.2%)	100 (17.9%)	457 (18.2%)
Hurley stage II	2,115 (69.0%)	436 (78.1%)	1,679 (66.9%)
Hurley stage III	352 (11.5%)	21 (3.8%)	331 (13.2%)

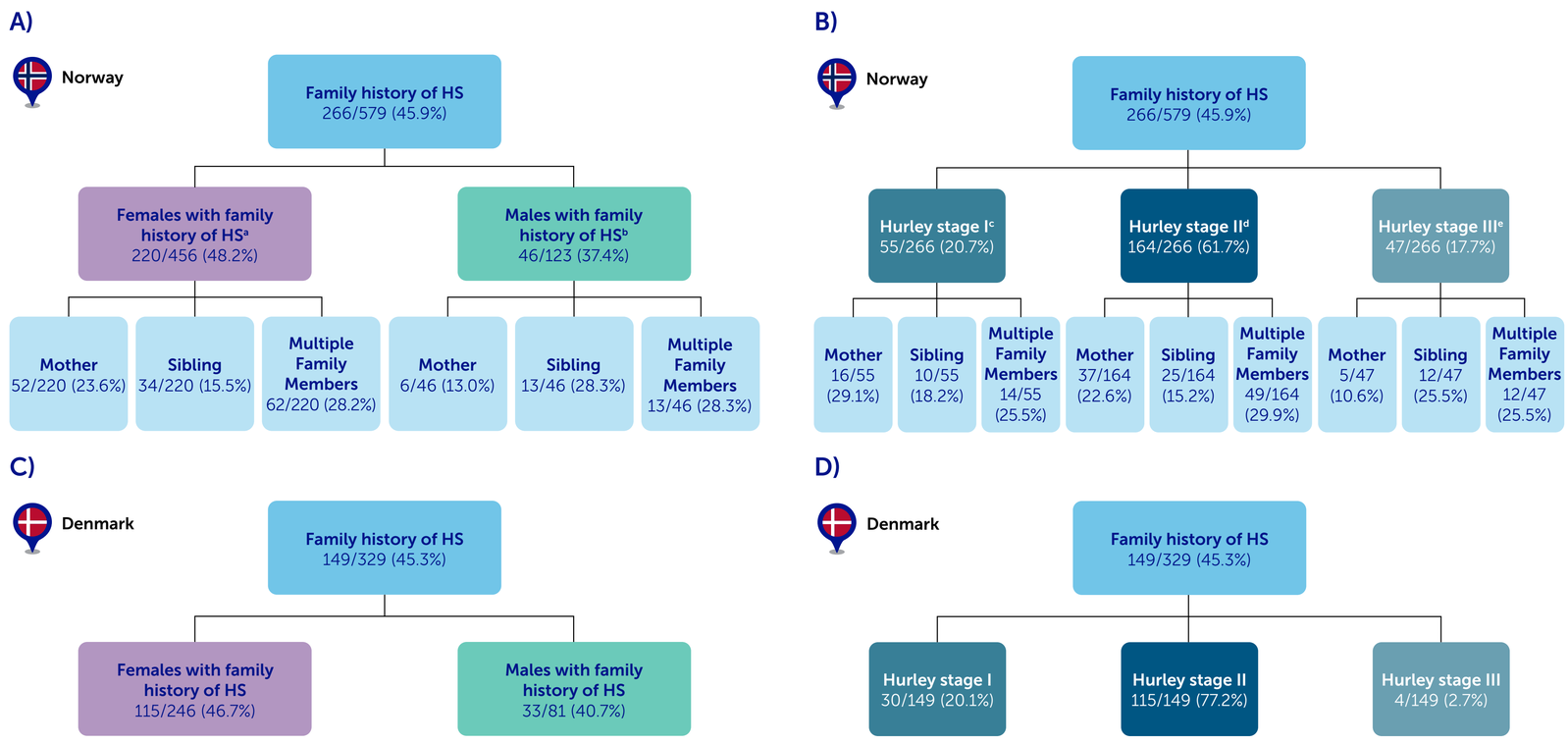
N values represent the overall number of patients in HISREG; n values exclude patients with missing data. Missing data, n, Denmark: sex, 2; Hurley stage, 1; age, 7. Missing data, n, Norway: sex, 2; Hurley stage, 42; age, 10. Missing data, n, %, total cohort: sex, 4 (0.1%); Hurley stage, 43 (1.4%); age, 17 (0.6%).

Figure 1 Age at first symptom (disease onset), first GP visit and first dermatologist visit in patients with HS



N values represent the overall number of patients in each population; n values exclude patients with missing data for each outcome. Overall population: Missing data, n: age at first symptom, 71; age at first GP visit, 891; age at first dermatologist visit, 1,020. Female population: Missing data, n: age at first symptom, 51; age at first GP visit, 650; age at first dermatologist visit, 759. Male population: Missing data, n: age at first symptom, 20; age at first GP visit, 237; age at first dermatologist visit, 257. Denmark: Missing data, n: age at first symptom, 2; age at first GP visit, 189; age at first dermatologist visit, 214. Norway: Missing data, n: age at first symptom, 69; age at first GP visit, 702; age at first dermatologist visit, 806.

Figure 2 Family history of HS by sex and disease severity



N numbers represent the total number of patients in that subgroup (Norway, Female, Male, Hurley stage I, II or III) with available data. n values present those within each subgroup who have a positive family history of HS. A) Missing data, n, %: family history, 300 (34.1%); sex, 0 (0.0%); family member with HS in the female population, 5 (2.3%); family member with HS in the male population, 2 (4.3%). B) Missing data, n, %: family history, 300 (34.1%); Hurley stage, 5 (0.6%); family member with HS in Hurley stage I, II or III population; 0, (0.0%), 4 (2.4%), 3 (6.4%), respectively. **[a-e]** Other Family Member or not reported, n/N (%): 72/220 (32.7%); 14/46 (30.4%); 15/55 (27.2%); 53/164 (32.3%); 18/47 (38.3%), respectively.

GP: general practitioner; **HS:** hidradenitis suppurativa; **HISREG:** Clinical Scandinavian Registry for Hidradenitis Suppurativa.

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