



Seven Years to a Name: A Narrative Review of Delayed Recognition of Hidradenitis Suppurativa and the Cost of the Diagnostic Journey to Patients

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Abstract

Hidradenitis suppurativa is painful, visible, and diagnosed on history and examination without a single laboratory test. It also takes the better part of a decade to name. The gap between how easy the diagnosis is and how long it takes is the subject of this review.

Objectives: To review the published evidence on diagnostic delay in hidradenitis suppurativa: how long it lasts, where in the pathway the time is lost, what it costs the patient, and whether it has improved.

Material and Methods: Narrative review of international surveys, national cohorts, guideline documents, randomised trials of systemic therapy and qualitative studies indexed in PubMed and the major dermatology journals. No new patient data were generated; every estimate quoted is one published by the original investigators.

Results: In a survey of 517 patients with hidradenitis suppurativa and 516 with psoriasis across 24 countries, mean delay from first physician visit to diagnosis was 7.2 years against 1.6 years for psoriasis, and mean delay from symptom onset to first visit was 2.3 against 1.0 years. A delay of more than two years was reported by 73.3 per cent of patients with hidradenitis suppurativa against 26.7 per cent with psoriasis. Later national cohorts reported delays of 8.4 years in France, 10.0 in Germany and 10.1 in Portugal.

Conclusion: Roughly three quarters of the delay occurs after the patient has already presented to a doctor, which locates the problem in recognition rather than in help-seeking. Studies published across nearly two decades show no improvement, and the delay matters more now than it did, because effective systemic treatment exists and irreversible scarring accumulates while the diagnosis is missed.

Abbreviations: HS – Hidradenitis Suppurativa, DLQI – Dermatology Life Quality Index, IHS4 – International Hidradenitis Suppurativa Severity Score System, TNF – Tumour Necrosis Factor, IL – Interleukin, GP – General Practitioner.

Keywords: Hidradenitis Suppurativa; Diagnostic Delay; Primary Care; Misdiagnosis; Quality of Life

Introduction

Hidradenitis suppurativa is a chronic inflammatory disease of the follicular unit, producing painful nodules, abscesses, draining tunnels and scarring in the axillae, groin, perineum and under the breasts [1,2]. Prevalence estimates cluster around 1 per cent in European populations, making it substantially commoner than most conditions dermatologists are confident about diagnosing [3,4].

The diagnosis rests on three clinical features: typical lesions, typical sites, and recurrence [5,6]. There is no confirmatory test, no biopsy requirement and no imaging criterion. In principle it should be among the fastest diagnoses in medicine.

In practice it is among the slowest. Patients describe years of individual abscesses treated as isolated infections, repeated courses of antibiotics, and incision and drainage procedures that provide temporary relief and permanent scars [7,8]. This review sets out how long the delay is, where in the pathway it accrues, what it costs, and whether two decades of professional attention have shortened it.

Material and Methods

Search strategy: PubMed and the archives of the major dermatology and primary care journals were searched for studies of diagnosis, delay and misdiagnosis in hidradenitis suppurativa. Search terms combined hidradenitis suppurativa and acne inversa with diagnostic delay, misdiagnosis, primary care, referral, quality of life and stigma. Reference lists of European and North American guidance [5,9,10] were screened by hand for primary sources.

Eligibility: Studies were included if they quantified the interval from symptom onset or first consultation to diagnosis, reported misdiagnosis or referral patterns, or measured the consequences of delay. Trials of systemic therapy are cited to establish what is being delayed and are identified as such.

Data extraction and handling: Design, setting, sample size, how the interval was defined and the reported estimate were extracted as published. Whether the interval measured runs from symptom onset or from first medical contact is reported alongside every figure, because the two differ by years and are frequently conflated. No pooling or re-analysis was performed. Figures 1 to 4 and Tables 1 and 2 reproduce published values only. This is a narrative synthesis and was not registered as a systematic review.

Results

The comparison that makes the point: The most informative study surveyed 517 patients with hidradenitis suppurativa and 516 with psoriasis across 24 countries, asking each how long it took to see a doctor and then to receive a diagnosis. Mean delay from first physician visit to diagnosis was 7.2 years for hidradenitis suppurativa against 1.6 years for

psoriasis (Figure 1) [11]. Psoriasis is the right comparator: also chronic, also inflammatory, also diagnosed clinically by a dermatologist. The difference is not explained by the difficulty of the diagnosis.

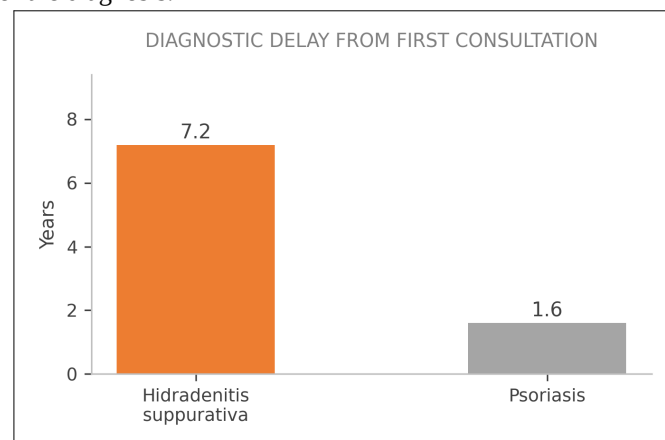


Figure 1: Mean diagnostic delay from first physician visit, hidradenitis suppurativa against psoriasis, across 24 countries [11]

Where the time goes: The same survey separated patient delay from system delay. Mean time from symptom onset to first physician visit was 2.3 years for hidradenitis suppurativa and 1.0 year for psoriasis; mean time from that visit to diagnosis was 7.2 and 1.6 years respectively (Figure 2) [11]. Patients with hidradenitis suppurativa do wait longer before seeking help, which embarrassment about the sites involved plausibly explains [7,12]. But roughly three quarters of the total delay accrues after they have already presented. The problem is predominantly one of recognition, not of help-seeking.

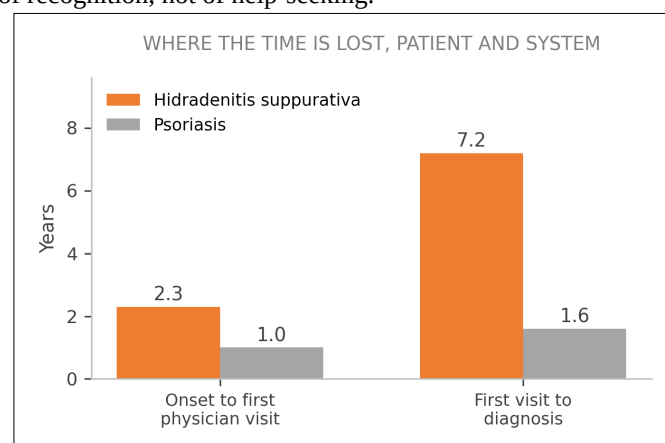


Figure 2: Delay before and after first medical contact in hidradenitis suppurativa and psoriasis [11]

How widespread: A delay of more than two years was reported by 73.3 per cent of patients with hidradenitis suppurativa against 26.7 per cent of those with psoriasis (Figure 3), and within the hidradenitis group women and those with moderate or severe disease were more likely to experience it [11]. This is not a long tail of unusual cases; it is the typical experience.

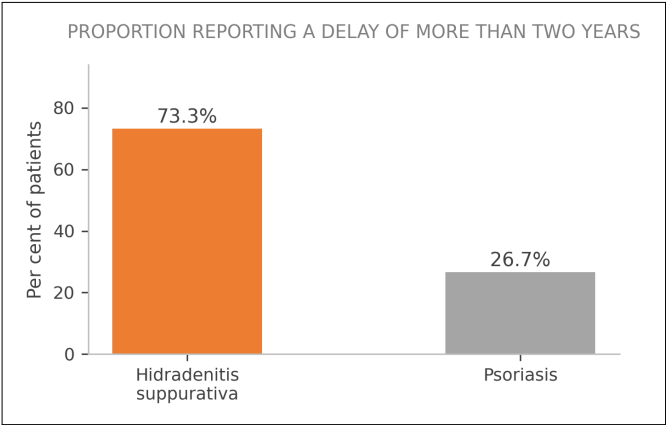


Figure 3: Proportion of patients reporting a diagnostic delay exceeding two years [11]

Whether it has improved: It has not. National cohorts published subsequently report mean delays of 8.4 years in France, 10.0 years in Germany and 10.1 years in Portugal (Figure 4) [13,14,15]. The Portuguese authors noted explicitly that their finding demonstrated the absence of improvement across seventeen years of increasing professional interest in the disease [15]. Analyses of multinational survey data have identified misdiagnosis, delayed specialist referral and patient embarrassment as the factors with the most supporting evidence, alongside associations with ethnicity, smoking, body mass index, comorbidity and employment status [16].

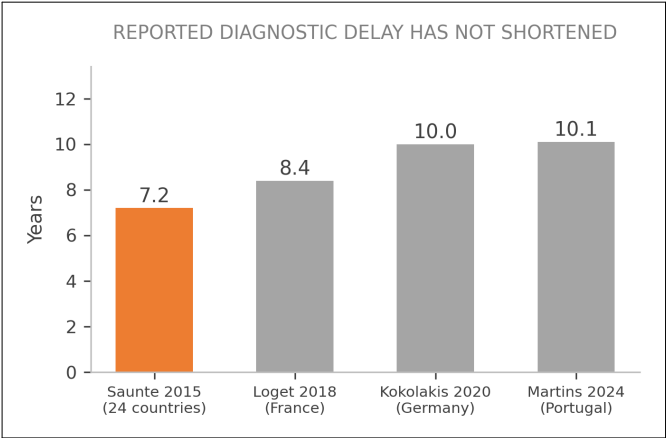


Figure 4: Mean diagnostic delay reported in successive cohorts [11,13,14,15]

Study	Design and cohort	Principal reported finding
Saunte et al. 2015 [11]	Survey, 517 HS and 516 psoriasis, 24 countries	Delay 7.2 vs 1.6 years; 73.3% vs 26.7% delayed over 2 years
Loget et al. 2018 [13]	R-ENS Verneuil study, France	Mean delay 8.4 years; misdiagnosis a major contributor
Kokolakis et al. 2020 [14]	National cohort, Germany	Mean delay 10.0 years; effects on patients and health system
Martins et al. 2024 [15]	Cohort, Portugal	Mean delay 10.1 years; no improvement over 17 years
Rick et al. 2021 [12]	Patient survey of misdiagnoses and barriers	Documents repeated misdiagnosis before correct labelling
Kimball et al. 2016 [17]	PIONEER I and II, adalimumab	Established the first licensed systemic therapy
Kimball et al. 2023 [18]	SUNSHINE and SUNRISE, secukinumab	Second biologic class with randomised support

Table 1: Principal studies reviewed, with the finding as reported by the original investigators

What is being delayed: The cost of delay has risen because the treatment has improved. Adalimumab was the first systemic therapy with randomised support in moderate to severe disease [17], secukinumab followed with two further randomised trials [18], and additional agents are in development [19]. Guidance now sets out a staged approach from topical and antibiotic therapy through biologics to surgery [5,9,10]. A patient diagnosed at year one enters that pathway; a patient diagnosed at year ten enters it with established tunnels and scarring that no anti-inflammatory drug reverses [20,21], and dermal tunnels predict slower response to biologics [35].

What the delay costs: Quality of life scores in hidradenitis suppurativa are among the worst recorded in dermatology, exceeding those in psoriasis and atopic dermatitis [22,23]. Pain is the dominant symptom and is frequently under-treated [24]. Depression and anxiety are substantially more common than in the general population [25,26], and the sites involved, together with malodour from draining lesions, produce a pattern of concealment and social withdrawal that qualitative work documents consistently [7,27], with resilience emerging as a modifier of that burden [30]. Repeated incision and drainage, which is what a lesion misidentified as a simple abscess receives, provides short-lived relief and contributes to the scarring [8,28]. The pattern is visible in utilisation and cost data [34], and modelling favours earlier diagnosis economically as well as clinically [33].

Stage	What happens	Contribution to delay
Symptom onset	Painful nodules, often attributed to shaving or hygiene	2.3 years before first consultation [11]
First presentations	Individual lesions treated as isolated abscesses	Antibiotics and drainage without a unifying diagnosis [8,12]
Recurrence	Pattern not recognised as one disease	The single largest contributor [11,16]
Referral	Delay in reaching dermatology	Identified as a principal driver [16]
Diagnosis	Clinical, on lesions, sites and recurrence	No test required; 7.2 years after first visit [5,11]
Treatment	Staged medical therapy, surgery for tunnels	Scarring accrued in the interval is irreversible [20,21]

Table 2: The diagnostic pathway in hidradenitis suppurativa and where the delay accumulates

Discussion

The central finding of this literature is a comparison rather than a number. Two chronic inflammatory skin diseases, both diagnosed clinically, both managed by dermatologists, surveyed in the same study with the same instrument: 7.2 years against 1.6 [11]. Whatever explains that gap, it is not diagnostic difficulty, because hidradenitis suppurativa has simpler criteria than psoriasis does.

The more useful finding is the split between patient delay and system delay. Patients do take longer to present, and given the sites involved that is unsurprising [7,12]. But 7.2 of the roughly 9.5 years elapse after the patient is already in front of a clinician [11]. Interventions aimed at encouraging earlier help-seeking address the smaller share of the problem. What the data point to is a recognition failure among clinicians who are, by definition, already seeing the patient.

The mechanism of that failure is visible in how the disease presents. A single fluctuant painful lesion in the axilla is an abscess, and treating it as one is reasonable. The diagnosis depends on noticing recurrence, and recurrence is only visible to someone who sees the same patient repeatedly or reads the notes of those who did. In systems where each episode is managed by whoever is available, in urgent care or in an emergency department, the pattern that constitutes the diagnosis is precisely the information the system does not retain [8,12,16].

Two further points deserve emphasis. First, the delay has not improved: cohorts published in 2018, 2020 and 2024 report figures at or above the 2015 international survey [13,14,15]. Awareness campaigns, guidelines and new licensed drugs have not shortened it, which suggests the barrier is structural rather than educational. Second, the cost of delay is higher now than when these delays were first measured. When no effective systemic therapy existed, a late diagnosis lost the patient little beyond a name. Now it loses them years of treatment during which tunnels and scarring accumulate irreversibly [17,18,20,21].

Study limitations

The limitations belong to the underlying literature. Almost all delay estimates are patient-recalled and retrospective, and recalling the year symptoms began is unreliable over a decade [11,15]. Cohorts are recruited in specialist dermatology clinics, so they describe patients who eventually reached a diagnosis and cannot count those still undiagnosed, which biases the estimate downwards. Definitions of the interval differ between studies, some measuring from symptom onset and others from first consultation [11,13,14]. Comparison with psoriasis is informative but not randomised, and the two populations differ in age, sex distribution and comorbidity [11]. Prevalence estimates vary several-fold with ascertainment method [3,4,29,31]. The consequences of delay are inferred from cross-sectional associations rather than demonstrated prospectively [20,22]. And the literature is overwhelmingly European and North American [16,32].

Conclusion

A patient with recurrent painful lesions in the axillae and groin has a diagnosis that requires no test and takes, on average, more than seven years to make after they first ask a doctor about it. The comparison with psoriasis, 1.6 years in the same survey, removes difficulty as an explanation. Most of the delay happens inside the health system rather than before the patient enters it, and it has not shortened across two decades of increasing professional attention. The practical implication is narrow enough to state in a sentence: a second abscess in the same flexural site is not a second abscess, and asking whether it has happened before is the whole diagnostic test.

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Conflict of Interest

The authors declare no competing interests.

Ethics Statement

This article reviews previously published studies only. No new patient data were collected and no participants were recruited, so ethical approval was not required.

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