Why hidradenitis suppurativa takes seven years to diagnose

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Hidradenitis suppurativa (HS) is a chronic, inflammatory skin condition characterised by painful nodules, abscesses, and sinus tracts, primarily affecting apocrine gland-bearing areas. Despite its debilitating nature and significant impact on quality of life, patients frequently endure a prolonged journey to diagnosis, often navigating years of misidentification and ineffective treatments. This diagnostic odyssey not only delays appropriate management but also allows the disease to progress, leading to more severe and entrenched pathology.

KEY TAKEAWAYS

- The Pivot: The median diagnostic delay for hidradenitis suppurativa stands at approximately seven years, a period during which patients experience significant disease progression and psychological distress.
- The Data: Misdiagnosis is common, with conditions like folliculitis, boils, and sexually transmitted infections frequently cited as initial incorrect diagnoses.
- The Action: Clinicians, particularly in primary care and emergency departments, must improve recognition of HS's characteristic lesions and anatomical distribution to shorten the diagnostic timeline.

Hidradenitis suppurativa is a chronic inflammatory dermatosis that manifests with recurrent, painful nodules, abscesses, sinus tracts, and scarring. The disease primarily affects intertriginous areas such as the axillae, groin, inframammary folds, and perineum. Its aetiology is complex, involving follicular occlusion, immune dysregulation, and genetic predisposition. The clinical presentation can vary widely, from isolated lesions to extensive, interconnected sinus tracts that drain purulent material, leading to significant pain, odour, and disfigurement. This variability contributes to the diagnostic challenge, as early-stage HS can mimic more common dermatological conditions.

The unmet need in HS is substantial, driven largely by the profound impact on patients' physical and mental health. Chronic pain, restricted movement, social stigma, and psychological distress are common. Patients often report feelings of isolation, anxiety, and depression, which are exacerbated by the persistent nature of the disease and the frustration of delayed diagnosis. The economic burden is also considerable, encompassing direct medical costs from repeated consultations, emergency visits, and surgical interventions, as well as indirect costs from lost productivity and disability.

The Diagnostic Labyrinth

The journey to an accurate HS diagnosis is notoriously protracted, with a median delay often cited as seven years. This extended period is not merely an inconvenience; it represents years of untreated inflammation, progressive tissue destruction, and profound patient suffering. The delay is multifactorial, stemming from a lack of awareness among

healthcare professionals, the non-specific nature of early symptoms, and the tendency for HS lesions to be mistaken for other conditions. Patients frequently cycle through multiple clinicians, including general practitioners, dermatologists, gynaecologists, and even surgeons, before receiving a correct diagnosis.

Initial misdiagnoses are common. Folliculitis, furunculosis (boils), carbuncles, and cellulitis are frequent culprits, particularly in primary care settings where acute presentations of HS may be mistaken for bacterial infections. Other conditions that mimic HS include epidermoid cysts, pilonidal cysts, Crohn's disease (especially perianal involvement), and even sexually transmitted infections. The anatomical distribution of HS lesions, particularly in the genital and perianal regions, can further complicate diagnosis, leading to misdirection towards gynaecological or proctological evaluations. This diagnostic ambiguity highlights the need for a heightened index of suspicion among all clinicians encountering patients with recurrent inflammatory lesions in characteristic areas.

Where the Delay Occurs

The diagnostic delay for hidradenitis suppurativa is not confined to a single point in the healthcare system; it is a systemic issue spanning primary care, emergency departments, and even specialist referrals. Primary care physicians are often the first point of contact for patients presenting with skin lesions. Without specific training or experience in recognising HS, these clinicians may attribute symptoms to more common, less severe conditions, initiating a cycle of ineffective antibiotic courses or incision and drainage procedures that provide only temporary relief. The mental shortcuts inherent in busy general practice can lead to anchoring bias, where an initial misdiagnosis persists despite evolving clinical signs.

Emergency departments also play a role in this delay. Patients with acute, painful HS abscesses often present to the ED for symptomatic relief. Here, the focus is typically on acute management of infection and pain, with less emphasis on establishing a definitive underlying diagnosis for recurrent lesions. Incision and drainage may be performed, but the opportunity to consider HS as the root cause is frequently missed, perpetuating the cycle of episodic care without addressing the chronic inflammatory process. This is particularly true for conditions like chronic urticaria, where diagnostic tests often yield little insight.

Even within dermatology, delays can occur. While dermatologists are best equipped to diagnose HS, patients may not be referred to them in a timely manner, or they may encounter dermatologists less familiar with the nuances of HS presentation. The disease's spectrum, from mild to severe, means that early, less typical presentations can still be overlooked. The psychological impact of HS can lead to patient reluctance in seeking care or openly discussing symptoms, especially those affecting sensitive areas, contributing to self-imposed delays in presentation.

Clinical Features and Diagnostic Criteria

Accurate diagnosis of HS relies on a combination of clinical features. The key diagnostic criteria include the presence of typical lesions (nodules, abscesses, sinus tracts, scarring), characteristic anatomical distribution (axillae, groin, perineum, inframammary folds), and recurrence of lesions. The Hurley staging system, which classifies HS into three stages based on disease severity and extent of scarring, is a vital tool for assessment and treatment planning, but it is applied only after diagnosis. Early recognition of recurrent inflammatory lesions in the characteristic sites should prompt consideration of HS, even in the absence of extensive scarring or sinus tracts.

Physical examination is paramount. Palpation of affected areas can reveal subcutaneous induration and tenderness, even before overt lesions are visible. Careful inspection for double-headed comedones, which are pathognomonic for HS, can

be a valuable clue. These are often overlooked but represent follicular occlusion, a primary event in HS pathogenesis. The presence of multiple lesions, particularly if they are bilateral or involve more than one anatomical site, should raise suspicion for HS over isolated infections. A detailed patient history, focusing on the chronicity, recurrence, and location of lesions, is also critical. Patients often report a history of 'boils' that never fully resolve or recur in the same areas.
Differential diagnoses must be carefully considered. Beyond the common misdiagnoses, other conditions like Crohn's disease, especially with perianal involvement, can present similarly. Follicular occlusion syndrome, a broader term encompassing HS, acne conglobata, and dissecting cellulitis of the scalp, highlights the shared pathogenic mechanisms and potential for co-occurrence. The Oxford Handbook of Medical Dermatology provides a concise guide to navigating these complex presentations.

Impact of Delayed Diagnosis

The consequences of a seven-year diagnostic delay are severe and far-reaching. From a clinical perspective, delayed diagnosis means delayed initiation of effective treatment. HS is a progressive disease; without intervention, inflammation can lead to irreversible tissue damage, extensive scarring, and the formation of deep, interconnected sinus tracts. These advanced lesions are more challenging to treat, often requiring surgical intervention in addition to medical therapies. The chronic inflammation also increases the risk of complications such as squamous cell carcinoma in long-standing lesions, although this is rare.
For patients, the impact extends beyond physical symptoms. The chronic pain, malodour, and visible lesions can lead to significant psychological distress, social isolation, and impaired quality of life. Many patients report feelings of shame and embarrassment, leading to avoidance of social activities, intimate relationships, and even employment. The constant search for a diagnosis, coupled with ineffective treatments, can erode trust in the healthcare system and contribute to feelings of hopelessness. This prolonged suffering is entirely preventable with earlier recognition and appropriate management. The diagnostic journey for conditions like Sjögren's Disease also highlights the profound impact of such delays.
The current standard of care for HS involves a multidisciplinary approach, combining medical therapies with surgical interventions. Biologic agents, particularly TNF-alpha inhibitors, have revolutionised treatment for moderate to severe HS, demonstrating efficacy in reducing inflammatory lesion counts and preventing disease progression. Topical and systemic antibiotics, retinoids, and hormonal therapies also play a role, especially in milder cases or as adjuncts. Surgical options range from local excision of individual lesions to wide excisions and reconstructive surgery for extensive disease. The effectiveness of these treatments is maximised when initiated early in the disease course, before irreversible damage has occurred.

Moving Towards Earlier Recognition

Addressing the diagnostic delay in HS requires a concerted effort across all levels of healthcare. Education and awareness campaigns targeting primary care physicians, emergency department staff, and other non-dermatology specialists are essential for patient outcomes. These initiatives should focus on the characteristic clinical features of HS, its typical anatomical distribution, and the importance of considering HS in patients with recurrent inflammatory lesions, even in the absence of classic scarring. Simple diagnostic algorithms or checklists could aid in early identification.
Patient empowerment also plays a role. Educating patients about HS symptoms and encouraging them to advocate for a

thorough evaluation can shorten the diagnostic timeline. Support groups and patient advocacy organisations are vital in this regard, providing resources and fostering a sense of community. The goal is to reduce the median diagnostic delay from seven years to a more acceptable timeframe, ensuring that patients receive timely access to effective treatments and multidisciplinary care. This would not only alleviate suffering but also prevent the long-term complications associated with untreated, progressive disease.

CLINICAL IMPLICATIONS

The persistent seven-year diagnostic delay in hidradenitis suppurativa is a clinical failure that demands immediate attention. General practitioners and emergency physicians are on the front lines, and their lack of familiarity with HS's varied presentations means patients are often misdiagnosed with common infections, leading to repeated, ineffective antibiotic courses and unnecessary procedures. This pattern of care not only prolongs patient suffering but also allows the disease to progress unchecked, making subsequent treatment more challenging.

Dermatologists, while specialists, must also be vigilant. The early stages of HS can be subtle, and a high index of suspicion is required, especially in patients presenting with recurrent inflammatory lesions in characteristic intertriginous areas. Relying solely on advanced scarring or sinus tracts for diagnosis means missing opportunities for early intervention, which is critical for preventing irreversible tissue damage and improving long-term outcomes. The current therapeutic market, with effective biologics available, makes this delay even more egregious.

For patients, this delay translates into years of chronic pain, psychological distress, and social isolation. The frustration of being dismissed or misdiagnosed can erode trust in the medical system. Industry, too, has a role in supporting educational initiatives for non-dermatology specialists, ensuring that the benefits of newer therapies can reach patients earlier in their disease course. Reducing this diagnostic gap is not just about improving clinical pathways; it is about restoring quality of life for a vulnerable patient population.

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