HIDRADENITIS SUPPURATIVA: THE UNDERCOVER SKIN DISEASE

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The motivation for this two-part series is to help provide awareness across nursing regarding hidradenitis suppurativa (HS) or acne inversa as it is otherwise known. This first article explores the history and background of HS, while the second article examines the assessment, diagnosis, and treatment of HS. This two-part article is written from the author's perspective and consideration should be made for varying approaches to practice and research.

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- Nursing
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- Patient outcomes

Hidradenitis suppurativa (HS) is a painful and chronic skin disease that causes abscesses and scarring to the skin. The believed pathophysiology of HS has evolved over the years and medical and technological advances may have contributed towards this. It is documented that the condition affects up to 4% of the world's population; however, the actual figure may be higher.

People with HS can suffer to varying degrees, from Hurley stage 1-3 (mild to severe). Poor recognition and late diagnosis by clinicians external to dermatology are factors that may contribute towards disease progression and the worsening of symptoms, which can influence patient outcomes. It is felt that raising awareness in both primary and secondary care can help patients to access the treatments they need quicker and help to prevent the permanent physical side effects of HS, such as scarring and potential partial loss of function of the affected site(s).

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Hidradenitis suppurativa is known to cause psychological morbidity and can impact on the quality of life of those affected. People with HS need education and support from health professionals to better manage the symptoms of their HS and overall health, as poor lifestyle choices may influence disease severity. The potential contributing factors for HS, many myths surrounding HS and top tips for treatment will be discussed. To identify the needs of people that suffer with HS, primary surveying is required to understand the patient's journey from first presentation to diagnosis, to therefore facilitate early diagnosis and meet the needs of people that suffer with HS.

Hidradenitis suppurativa in context

The term hidradenitis suppurativa comes from the Latin, 'hydro' meaning water, or in this context 'sweat', and 'adenitis', meaning inflammation of the gland. It is a chronic and inflammatory skin disease encompassing inflammation of the hair follicles and has a predilection for the intertriginous regions of the body, which includes the inguinal, axillary, genital, perineal, and perianal areas.[1,2] This condition presents in otherwise healthy individuals and rarely appears prior to puberty. The disease is insidious and primary presentation can begin with erythema to the skin.[3,4] It can cause grave morbidity, including painful nodules, boils and abscesses with suppuration, draining sinus tracts throughout multiple regions of the body, and scarring. Furthermore, it is recognised as having a profound psychological impact on sufferers, in turn, affecting quality of life.[5,6] Hidradenitis suppurativa is known to cause functional impairment to the extent comparable to cardiovascular disease, type 2 diabetes and renal failure. The causation is associated pain, purulent suppuration and scarring.[7-11]

Smoking, alcohol abuse, and diabetes is more prevalent among people with HS compared to the general population.[12,13,14] Depression, anxiety, and suicidality is also more common.[13,14] and this is supported by the increased use of antidepressant and anxiolytic drug use among this cohort.[13]

The estimated prevalence of HS is 0.1–4% worldwide.[15-23] Research shows that incidence rates have increased to as high as 11.4 per 100,000 patients in the United States.[24] In a study by Ingram et al,[23] HS prevalence was documented as 0.77% (n= 33,110) from a United Kingdom (UK) population of 4.3 million. This figure was determined by examining research standard medical records and identified patients using rigorous diagnostic criteria, and through this process managed to include previously undiagnosed patients.

The clinical presentation of HS is distinct, and a diagnosis can be determined from basic questioning

It is already recognised that there is an average diagnostic delay of seven years in the UK for people suffering with HS[25] and HS remains under-recognised by clinicians, which is evident from the documented timeframes from initial presentation to definitive diagnosis.[26] This study did not capture the number of people suffering in silence with HS who choose not to seek medical care, and as such the numbers may not be reflective of the entire population of people with the condition. Some of the reasons for this could include embarrassment, a lack of confidence in health professionals, a fear of judgement and a lack of awareness that the symptoms of the disease are not caused by the person's actions. Nevertheless, unhealthy behaviours may make symptoms worse.

For some time, HS has been considered a rare disease unfamiliar to GPs and nurses functioning within primary care. Patients with HS tend to first present in accident and emergency (A&E), to their GP or even at a sexual health clinic or private centre. It is recognised that the disease is regularly seen by non-dermatologists and subsequently, overall disease burden is disproportionate to the approximate prevalence. Consequently, sufferers of HS may experience suboptimal care until the disease is identified and managed by a dermatologist.

The clinical presentation of HS is distinct, and a diagnosis can be determined from basic questioning.[27,28] HS is often misdiagnosed as furunculosis or "boils."[26] There are a number of patients with HS that require secondary care intervention and access to specialist treatments. Earlier detection at a milder stage and subsequent management may help to prevent its progression and the associated scarring. The resultant scarring can be extensive, and this can reduce the function of a body region and bring about severe impacts on quality of life and psychological wellbeing for the people that suffer. Subsequently, NHS services need to bridge the gaps and provide awareness among clinicians outside of dermatology. Moreover, public health awareness and better understanding can encourage people with HS to feel comfortable to seek medical help.[29] The British Association of Dermatologists (BAD) guideline on HS, published in 2019, provides guidance on the management of HS for both primary and secondary care health providers. It is formulated from current evidence and expert opinion[30] and helps clinicians to meet the needs of people with HS.

The history of hidradenitis suppurativa

In 1839, Velpeau (a French anatomist and surgeon) first described HS as a separate entity and recorded an account of a patient with a superficial abscess in the axillary, mammary, and perianal regions.[31] The disease later became known as Verneuil's disease because, in 1854, Verneuil linked the suppuration to the sweat glands. Nonetheless, it was soon called HS due to its presumed pathophysiology at that time, and this was determined by clinical features alone, as Verneuil did not perform histopathological examinations.[32]

In 1922, Schiefferdecker named the sweat glands eccrine and apocrine, and later associated HS to the apocrine glands.[33] In 1939, Brunsting recorded the histologic features of HS and its common link with acne, and that HS, dissecting cellulitis of the scalp and the neck, and acne conglobata often presented in the same patient with follicular hyperkeratinisation and a secondary bacterial infection.[34] In 1956, Pillsbury et al, united acne conglobata, HS, and dissecting cellulitis under the term follicular occlusion triad;[35] the error in this notion was the connection to the apocrine sweat glands. In 1975, Plewig and Kligman added pilonidal sinus as an additional element and the term 'acne tetrad' was first introduced. Furthermore, they highlighted that HS is misleading due to a dearth of apocrine gland involvement, however, they failed to detail an account of this. HS was later recognised as an acneiform condition that activates with follicular occlusion as opposed to an infection of the sweat glands.[36,37]

Hidradenitis suppurativa implies a false pathogenetic notion based on historical beliefs regarding clinical presentation as opposed to the occlusion of the hair follicles

HS implies a false pathogenetic notion based on historical beliefs regarding clinical presentation as opposed to the occlusion of the hair follicles. This also occurs in acne vulgaris, for which it shares histopathological and clinical characteristics set apart by the anatomical location of HS in apocrine gland abundant regions. Acne inversa describes the involvement of intertriginous locations as opposed to the sites commonly affected with acne and as such it is felt that the name 'acne inversa' seems more appropriate than HS.[37,38]

Demographics

The incidence of HS seems to have risen in recent years; however, this may be attributed to greater awareness, more accurate diagnosis, and a higher presentation rate to clinicians. HS is three times as prevalent for women than men in the general population.[6] The majority of cases that present tend to be young to middle-aged adults[22] and HS most commonly develops in adults in their early 20s with an average age of 22.1 years, but can present at any age.[26] The disease normally continues throughout adult life, and seems less severe in women after menopause[39] and prevalence in general tends to reduce after the ages of 50-55 years.[26,40] HS seems two to three times more prevalent in African American and biracial people compared with white skinned people.[22] Genetics may influence HS and research demonstrates that a third of people diagnosed with HS have a family member also living with this skin condition.[41]

Loose fitting clothing is recommended to reduce occlusion and friction

Contributing factors

The cause of HS is not known. There are several factors that may influence symptoms of HS and which may be considered contributing. These include:

- Aberrant immunity: a virus-specific immune response causes the pathological lesions, or viruses to suppress or sabotage adaptive immunity[42]
- Diet: in one survey study involving 47 patients who followed a dairy-free diet, no patients experienced disease progression and 83% improved to various degrees.[43] In another study, 12 subjects underwent surgical excision followed by diet modification with no wheat or brewer's yeast consumption with immediate disease stabilisation during a 12-month period of follow-up.[44] Further research is needed to allow for comprehensive diet counselling, and in the meantime patients should be advised to adhere to a healthy and natural diet
- Smoking is more common among people with HS than the general population, and the components of smoke are known to promote hyperkeratosis (causing follicular occlusion), increase inflammation and could potentially worsen the symptoms of HS.[45] Research has shown that the prevalence of HS seems greater amongst smokers than non-smokers or ex-smokers[26,28,40]
- Research has determined a link between HS and obesity.[26,28,40] Mechanical factors caused by skin to skin contact in obese patients can exacerbate symptoms which include friction from skin rubbing together and occlusion from loose or hanging skin
- Genetics may be involved,[41] as it is not uncommon for more than one person to suffer with HS within a family
- Bacteria may worsen the symptoms and skin inflammation and HS can respond to antibiotics, however some cultures from HS lesions are sterile.[46] Biofilms are associated with chronic HS and may account for why HS can become more resistant to medical management with progressive disease severity.[11] Biofilms are microscopic and appear as a shiny film (to the naked eye) over a surface of a wound. Biofilms are commonly generated from a mixture of strains of bacteria, fungi, yeasts, algae, microbes, and other cellular debris. These microorganisms adhere to the wound surface and secrete a viscous matter. Research has shown that 60-80%[47,48] of chronic wounds contain a biofilm. A meta-analysis by Malone et al[49] found biofilms present in 78.2% of chronic wounds
- Sex hormones may play a role as HS tends to present after puberty.[40] Women are affected by HS more than men and therefore a hormonal component has been hypothesised. Androgen, a type of hormone, can increase proliferation of the keratinocytes (skin cells), however the hormonal profile of patients with HS is usually found to be normal.[45] Several patients have reported a monthly cyclical flare during their menses, and this can present with enlarged lymph glands. Ultrasound scanning is therefore advised for persistently enlarged glands to rule out lymphadenopathy caused by malignancy.

The recorded prevalence of HS is comparative to other dermatological diseases such as psoriasis or eczema and therefore HS needs more attention

The many myths associated with hidradenitis suppurativa and top tips

- It is not caused by a person being overweight. People of all shapes and sizes suffer from HS and it has been known for a patient to lose weight with no or minimal benefit to their HS. Skin rubbing and occlusion can make symptoms worse, and it is of benefit to the person to maintain a healthy weight and size as per NHS recommendations
- It has not been proven that diet can exacerbate symptoms. A healthy and natural diet is always recommended for overall good health and wellbeing and patients can be directed to the 'Eatwell guide' on the NHS website
- It is not caused by a person being dirty or by poor hygiene.[26] Often people with HS wash more than once daily and with antibacterial lotions or washes
- Certain clothing may influence symptoms but is not the cause. Loose fitting clothing is recommended to reduce occlusion and friction. There are now companies that produce

garments specially designed for people with HS and structured to hold dressings in place over the commonly affected body sites. Stretchy net knickers are also beneficial because they can be washed, cut to size and are helpful for securing pads in place for the inguinal region

- Sprays seem to be preferred by patients as they can be used whilst avoiding the wounds, and also the pressure of rubbing or applying a roll-on or deodorant stick can cause additional discomfort. Powders are not advised due to their occluding nature and could build up in a wound and lead to infection
- Hair removal can be helpful. Waxing is often traumatic and painful because of wounds, and shaving can cause in-growing hairs and the hair to grow back thicker. In studies, laser hair removal improved HS by 32-72% after two to four months of treatment.[50] However, the treatment seems to work better in people with milder disease. Published studies suggest these lasers achieve from 65%-75% improvement in the axilla among patients with HS[51-53] although extensive scarring (more prevalent progressively with stage) can prevent lasers from working. The consensus is that non-ablative lasers are helpful in preventing new HS nodules, but are not helpful in treating patients with sinus tracts (present in stage 2 and 3) and theoretically undergoing laser hair removal at initial presentation of HS may improve outcomes with reference to scarring and disease progression. Aggressive laser treatment is advised (regular sessions every four to six weeks) and lasers work best on light-skinned people with dark hair, and are not ideal for people with grey or blonde hair as this prevents the laser from differentiating between skin and hair. The benefits of lasers is that they do not cause systemic side effects[54]
- What works for one does not work for all, and this should be considered when selecting treatments or giving advice. Establishing the patient's goals during their initial meeting can help to manage expectations
- HS is not contagious,[26,28,40] nor is it a sexually transmitted disease.

Summary

The number of people diagnosed with HS is increasing. The revised prevalence of HS is comparative to other chronic skin diseases and therefore HS needs more attention. People with HS require better support as the symptoms and associated psychological implications of the disease can impact heavily on a person's quality of life. Awareness of the disease amid clinicians in both primary and secondary care is essential for improving patient outcomes and examining the patient's journey from first presentation of symptoms to diagnosis could prove valuable for designing an effective and holistic HS service. DN

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