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Evaluation of the patient's journey with hidradenitis suppurativa at a dermatology service in Southern Brazil

Avaliação da jornada do paciente com hidradenite supurativa em um serviço de dermatologia no Sul do Brasil

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Abstract

Objectives: The objective of the study was to evaluate the epidemiological profile of patients with hidradenitis suppurativa (HS) referred to a tertiary dermatology center in southern Brazil, focusing on disease severity, diagnostic delay, and the number of physicians consulted before achieving a definitive diagnosis. **Methods**: A cross-sectional observational study was conducted through the analysis of medical records from patients diagnosed with HS who were referred to a dermatology outpatient clinic at a tertiary hospital in southern Brazil. Collected data included patients' clinical characteristics, disease severity, impact on quality of life (QoL), and the time elapsed and number of physicians consulted before diagnosis. **Results**: Nighty-six patients met the eligibility criteria for the study. Women predominated, with a mean age of 38.4 years. Disease severity scores indicated that most patients had moderate disease, with a significant impact on QoL. On average, patients consulted 5.1 physicians, and the mean time to establish a definitive diagnosis was 10.6 years. **Conclusions**: Increasing awareness of HS among healthcare professionals and patients is crucial in reducing diagnostic delays. Early recognition and effective screening, particularly in primary care, may enable timely treatment, reduce disease severity, and improve patient outcomes.

Keywords: Hidradenitis suppurativa. Diagnosis delay. Journey. Brazil.

Resumo

Objetivo: Avaliar o perfil epidemiológico de pacientes com hidradenite supurativa (HS) encaminhados a um centro terciário de dermatologia no sul do Brasil, com foco na gravidade da doença, no atraso diagnóstico e no número de médicos consultados até a obtenção do diagnóstico definitivo. **Métodos:** Foi realizado um estudo observacional transversal por meio da análise de prontuários de pacientes diagnosticados com HS e encaminhados ao ambulatório de dermatologia de um hospital terciário no sul do Brasil. Os dados coletados incluíram características clínicas dos pacientes, gravidade da doença, impacto na qualidade de vida, bem como o tempo decorrido e o número de médicos consultados até o diagnóstico. **Resultados:** Noventa e seis pacientes preencheram os critérios de elegibilidade do estudo. Houve predomínio do sexo feminino, e a média de idade foi de 38,4 anos. Os escores de gravidade indicaram que a maioria dos pacientes apresentava doença moderada, com impacto significativo na qualidade de vida. Em média, os pacientes consultaram 5,1 médicos e o tempo médio para estabelecimento do diagnóstico definitivo foi de 10,6 anos. **Conclusões:** O aumento da conscientização sobre a HS entre profissionais de saúde e pacientes é fundamental para reduzir o atraso no diagnóstico. O reconhecimento

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precoce e o rastreamento eficaz, especialmente na atenção primária, podem possibilitar o tratamento oportuno, reduzir a gravidade da doença e melhorar os desfechos dos pacientes.

Palavras-chave: Hidradenite supurativa. Atraso diagnóstico. Jornada. Brasil.

Introduction

Hidradenitis suppurativa (HS) is a chronic inflammatory systemic disease that usually affects intertriginous areas, originating from the occlusion of pilosebaceous units, leading to the formation of painful nodules, abscesses, fistulas, and scars.[1] The diagnosis of HS is clinical and based on the following three criteria: typical lesions, typical locations (intertriginous areas), and recurrence within 6 months.[1-3]

Without proper therapy, abscesses can recur and form fistulas with foul-smelling purulent exudate, which later become chronic lesions with draining sinus tracts and extensive fibrosis and scarring at the site.[4] These situations lead to a serious impact on patients' quality of life (QoL), resulting in difficulties with employment, personal and sexual relationships, isolation, and social stigma.[2,4-6]

The correct diagnosis of HS usually requires between 7 and 10 years[1,3,7,8] whilst the patient is referred to an average of 5 different doctors for various consultations, thus missing the "window of opportunity" for adequate disease treatment.[3,7,8] While dermatologists are the most qualified specialists to diagnose HS and minimize diagnostic delays, patients are typically initially seen by general practitioners and primary care physicians.[2,3] Limited awareness of HS among these frontline providers, along with limited access to dermatologists within the public healthcare system, leads to delays in diagnosis, specialist consultation, and the start of proper treatment.[9,10]

This study aimed to evaluate the epidemiological profile of patients with HS referred to a tertiary dermatology center in southern Brazil, focusing on disease severity, the number of physicians consulted before a definitive diagnosis, and the time elapsed between symptom onset and diagnosis.

Materials and methods

A cross-sectional observational study was conducted using the medical records of patients with HS evaluated at a specialized dermatology outpatient service at a tertiary hospital in southern Brazil between March 2023 and June 2024. The study was approved by the local Research Ethics Committee (CAAE: 73352123.1.0000.0020) in accordance with Resolution nº 466/2012 of the National Health Council and the Helsinki Conventions. The inclusion criteria included individuals aged 18 or older with complete medical records. Patients considered eligible signed the Informed Consent Form and were included in the study.

The data assessed included gender, age at diagnosis, age of symptom onset, time to diagnosis, number of doctors seen before proper diagnosis, disease severity, and impact on QoL. The Hurley classification and the International HS Severity Score System (IHS-4) were used to assess the disease severity. The Hurley classification assesses the presence of abscesses, tunnels, and scars, generating a classification in 3 stages of severity (1: absence of fistulas or scars; 2: the presence of fistulas and scars separated from each other; and 3: the presence of interconnected fistulas and scars). The IHS-4 corresponds to a mathematical score in which inflammatory nodules are multiplied by 1, abscesses by 2, and draining fistulas by 4. Mild conditions are scored 0-3 points, moderate conditions are 4-10 points, and severe conditions are 11+ points. The dermatology life quality index (DLQI) was used to assess the impact on daily life, with values > 10 indicating a severe impact on QoL.

The data were organized in Microsoft Excel® 2019 spreadsheets and statistically analyzed using IBM Statistical Package for the Social Sciences Statistics 29.0.2.0. Categorical data were presented as frequency tables, while quantitative variables were presented as descriptive measures (mean, median, standard deviation [SD], minimum, and maximum). The data were assessed for normality using the Kolmogorov-Smirnov test to verify bivariate statistical relationships. Due to the non-homogeneity of the data, the data were analyzed using Pearson's Chi-square test at the 5% significance level.

Results

Ninety-six patients were assessed, 71 women, and 25 men, with a mean age of 38.4 years (range, 14-68 years; median, 37 years; SD ± 13.7) (Table 1). The age at symptom onset ranged from 7 to 60 years, with a mean of 26.3 years (SD ± 13.7) and a median

Table 1. Characteristics of the patients with hidradenitis suppurativa regarding clinical and epidemiological aspects

Variable	n	%
Gender		
Male	25	26
Female	71	74
Age* (years)		
1-10	8	8
11-20	37	39
21-30	21	21
31-40	12	13
41-50	13	14
51-60	5	5
Hurley stage		
I	26	27
II	59	61
II	11	12
IHS-4		
Mild	41	43
Moderate	32	33
Severe	23	24

*Age at diagnosis.
n: number; HIS: international hidradenitis suppurativa severity score system.

of 24.0 years. The interval between symptom onset and diagnosis ranged from 6 months to 50 years, with a mean duration of 10.6 years and a median of 6 years (SD ± 7.1).

Before receiving a diagnosis of HS, patients reported consulting multiple healthcare professionals. On average, 5.1 physicians were consulted before a definitive diagnosis was established, with a range of 1 to 20 and a median of 3.

Most patients (61.4%) were classified as Hurley Stage II at the time of diagnosis, followed by 27.0% as Hurley Stage I and 11.4% as Hurley Stage III (Table 1). According to the IHS4 classification, 41 patients (42.7%) were categorized as having mild disease, followed by 33.3% with moderate disease and 24.0% with severe disease. The mean DLQI score at the time of HS diagnosis was 12.27, with a median of 12.5 and a SD ± 8.9.

Discussion

The prevalence of HS ranges from 0.00033% to 4.1% across studies.[1,9,11,12] There is still limited data on the true prevalence of the disease, both in Brazil and in other countries, due not only to diagnostic errors and delays but also to the time required to refer patients to specialized services, which can lead to a long and challenging journey.[1,3,13] The global prevalence of HS can vary widely,[1,11,13] reaching 8% in certain regions of the UK.[9] This high variation is due to geographical and ethnic influences, as well as diagnostic variations within the health system, which contribute to underdiagnosis of HS, making the exact prevalence still unknown, especially in Latin America.[12,14]

The initial manifestations of HS usually begin after puberty, mainly between the ages of 18 and 29, after the maturity of the apocrine glands.[2,14-16] Our data showed a mean age of 38.4 years (range 14-68 years with a median of 37 years), close to what Ianhez et at. presented in a study carried out with the Brazilian population, showing an average age of 40.4 years, demonstrating that HS is more prevalent among adolescents and adults than among children and older people.[14]

HS is often diagnosed with a significant delay after the onset of clinical symptoms. In this study, the time from symptom onset to diagnosis ranged from 6 months to 50 years, with an average of 10.6 years and a median of 6 years. The Global VOICE research projected a 10-year delay in disease diagnosis, and the German multicenter study PIRANHA reported a similar delay, whereas a Turkish study reported a shorter delay, averaging 5.8 years.[4,12] This variation in diagnosis time was also related to racial groups, with an average of 3.2 years in white patients, 4.8 years in blacks, 4.7 years in Hispanics, and 4.9 years for other ethnicities.[6]

In the present study, patients with HS consulted a mean of 5.1 physicians before receiving a definitive diagnosis, with a range of 1-20 and a median of 3. Chiricozzi et al. reported that patients consulted an average of 4-5 physicians before diagnosis, highlighting the substantial clinical journey required to obtain an accurate diagnosis.[3] Kokolakis et al. found that patients consulted a median of 3 healthcare professionals before receiving the correct diagnosis of HS, most commonly general practitioners, dermatologists, surgeons, and gynecologists, and that patients experienced an average of 4 misdiagnoses.[4] In 40-70% of cases, general practitioners constitute the first point of contact for patients with HS and subsequently refer them to various specialists, including general surgeons, coloproctologists, gynecologists, and dermatologists, depending on the clinical presentation.[2,17]

Dermatologists are the specialists best equipped to accurately diagnose and manage patients with HS, playing a crucial role in reducing diagnostic delays and initiating the most effective therapies during the early stages of the disease.[3,6,18] However, limited access to specialists and prolonged waiting times remain significant barriers to the timely initiation of appropriate care.[6,11]

Raising awareness of the disease among general practitioners and physicians from other medical specialties through continuing medical education programs is a key strategy for improving early recognition of HS. In addition, providing patients with information through various communication tools, such as online resources and educational leaflets, is essential. These approaches may significantly reduce the number of consultations required before diagnosis, facilitate accurate identification of the disease, preferably at earlier stages, and shorten the patient's diagnostic journey.[5,11]

Delays in HS diagnosis are associated with more advanced and/or symptomatic disease at the time of diagnosis. In the present study, most patients were diagnosed with moderate disease severity and elevated DLQI scores, reflecting extensive disease involvement and a substantial impact on QoL. This impairment in QoL is related to social isolation, sexual dysfunction, and difficulties in maintaining employment and interpersonal relationships. The prolonged diagnostic journey contributes to chronic disease progression, extensive scarring, limited mobility, and persistent pain, making HS a highly debilitating condition.[4,5,10]

Once the diagnosis of HS is made, treatment focuses on lifestyle changes, addressing comorbidities, and selecting the most appropriate drug therapy. Patients can induce clinical remission of HS by making lifestyle changes, such as increasing physical activity, quitting smoking, and losing weight.[19] Several comorbidities associated with HS, such as obesity, metabolic syndrome, depression, polycystic ovary syndrome, and arthritis, need to be addressed by different health care specialists. The care should involve not only the dermatologist, but also the endocrinologist, general surgeon, rheumatologist, gynecologist, psychiatrist, and others.[2,3] Research has shown that immunobiological therapy is crucial for preventing the progression of HS and improving patients' pain and QoL.[19-21] Early use of this medication is a "window of opportunity" to alter the natural progression of the disease, thereby reducing cumulative tissue damage. Delayed use of this therapy has been associated with a twofold lower likelihood of therapeutic response and a higher risk of disease exacerbations.[8]

The understanding of HS derives from European and United States studies. Latin America, on the other hand, has a different population profile, with a higher proportion of Black and Indigenous people. More studies, especially in Latin America, where socioeconomic aspects favor delays in the diagnosis and management of HS, are needed. The participation of more research centers with larger caseloads may help better assess the epidemiological, clinical, and psychosocial characteristics of HS in this population. Furthermore, studies that stratify patients by gender are essential to improve understanding of potential differences in disease presentation, severity, comorbidities, and QoL impairment, thereby contributing to more individualized and equitable approaches to diagnosis and treatment.

Conclusion

Increasing awareness of HS among healthcare professionals and patients is essential to reduce the significant diagnostic delay, which averaged 10 years and involved consultations with multiple physicians before a definitive diagnosis was reached. This delay contributes to disease progression, worsening both acute and chronic lesions, and results in the loss of the therapeutic window for early and appropriate treatment, including immunomodulatory therapies that may prevent progression and improve pain and QoL. Therefore, effective strategies, especially in primary care, are crucial for early identification and referral, helping to reduce disease severity and the overall burden on patients.

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Conflicts of interest

None.

Ethical considerations

Protection of humans and animals. The authors declare that no experiments involving humans or animals were conducted for this research.

Confidentiality, informed consent, and ethical approval. The authors have followed their institution's confidentiality protocols, obtained informed consent from patients, and received approval from the Ethics Committee. The SAGER guidelines were followed according to the nature of the study.

Declaration on the use of artificial intelligence. The authors declare that no generative artificial intelligence was used in the writing of this manuscript.

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