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Overview of care for hidradenitis suppurativa in the unified health system: a national epidemiological approach

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Abstract

This retrospective epidemiological study analyzed 106,172 outpatient visits related to Hidradenitis Suppurativa (HS) in Brazil between 2020 and 2024, using data from the Department of Informatics of the Unified Health System (DATASUS) to investigate demographic and geographical disparities. Women accounted for 59% of the cases, with the highest frequency between 21 and 30 years of age. A predominance of white (43%) and "pardo" (mixed-race) (35%) patients was observed, contrasting with the predominantly "pardo" composition of the Brazilian population according to the Brazilian Institute of Geography and Statistics (IBGE). Black and indigenous patients corresponded, respectively, to 6% and 0.008% of the records. Geospatial analysis identified higher visit rates (> 10/100,000 inhabitants) in Ceara, Rio Grande do Norte, Distrito Federal, and Paraná, while states in the North Region showed underreporting (Rondonia: <1/100,000). The number of consultations increased by 857% over the period, which may reflect both improvements in disease recognition and registration as well as a growing demand for specialized care. Despite this progress, we observed regional inequalities in access to healthcare, requiring targeted public policies, greater investment, infrastructure strengthening, training of professionals, and integration of care networks, especially in the North Region and rural areas, to guarantee the universal right to health and promote greater equity in care for HS patients in Brazil.

Keywords Hidradenitis suppurativa, Health disparities, Epidemiology, Brazil, Public health

1 Introduction

Hidradenitis Suppurativa (HS), a chronic inflammatory disease of complex etiology, is characterized by recurrent skin lesions, including painful nodules, abscesses, and fistulas in body folds such as the armpits, groin, and anal/genital region [1–8]. Its pathophysiology is not yet fully understood, but studies indicate that the process begins with follicular occlusion, followed by inflammation and rupture of the hair follicle, with subsequent involvement of the apocrine glands and local immunological infiltration [6–14]. Furthermore, a correlation between the levels proinflammatory cytokines, such as tumor

necrosis factor α (TNF-α) and interleukin IL1-β, and the severity of the pathology is described in the literature [13–16].

Despite the challenges posed by its debilitating nature, which is often associated with psychiatric comorbidities, work-related limitations, and a drastic reduction in quality of life, HS remains underdiagnosed and undertreated in various geographical contexts. This problem appears particularly pronounced in low and middle-income countries, where fragmented health systems and a shortage of specialists can make early diagnosis difficult. The global prevalence is estimated between 0.05% and 4%, with peaks observed among young women (aged between 20 and 40). However, significant regional discrepancies persist due to methodological differences and the potential underreporting of marginalized populations in epidemiological records [17].

In Brazil, the Unified Health System (SUS) provides universal healthcare to all citizens. However, significant socioeconomic and healthcare inequalities persist across the country, which can affect access to specialized care for chronic conditions like HS [18–20]. This limitation interferes with strategic resource allocation within dermatological care and covers essential regional and demographic differences, such as unequal access to specialized diagnostics in peripheral regions or among Indigenous populations [21].

In this context, the present study aimed to address these gaps through a retrospective, descriptive epidemiological analysis using publicly available data from the Department of Informatics of the Brazilian Unified Health System (DATASUS) [22].

2 Methods

2.1 Data source and extraction

This study is a retrospective and descriptive epidemiological analysis, based on public secondary data from the Department of Informatics of the Brazilian Unified Health System (DATASUS). The data are publicly available for research purposes via the DATASUS online portal (http://datasus.saude.gov.br/). The analysis included data from the SUS Outpatient Information System (SIA-PA/SUS), the main national database for consultations, clinical procedures, and therapies performed at the outpatient level, between January 2020 and December 2024." It is worth noting that until 2023 the inclusion of race/ethnicity was not mandatory, this may have caused a significant loss of data. Data extraction and processing were performed using the R programming language, version 4.5.0 [23], with the aid of the following packages: *microdatasus v2.3.1* [24], used for downloading, filtering, and structuring data from the SIA systems; *tidyverse v2.0* [25], for data manipulation, organization, visualization and descriptive statistical analysis; *geobr v1.9.1* [26],for spatial analysis and visualization, allowing geographic representation of cases and health services.

2.2 Inclusion criteria and study variables

We considered a HS patient when its principal ICD-10 code is equal to L732 (Hidradenitis Suppurativa) among all the registries SIA databases. Records lacking ICD code or performed outside SUS were excluded. Descriptive statistical analyses were conducted focusing on the frequency of HS-related reports and healthcare services, considering temporal, regional, and state distributions.

Because patient identifiers are anonymized, the data obtained could not be individually analyzed, thus, the descriptive analysis was based on the frequency of HS-related outpatient visits by age, sex, race/ethnicity, state, and year.

2.3 Data analysis

For analyze the geographic distribution, we calculated the number of consultations for HS patients per 100,000 general health consultations in the SUS, extracted from the SIA database. Race and ethnicity were self-declared by patients at the time of outpatient registration, following the classification categories established by the Brazilian Institute of Geography and Statistics (IBGE) [27]. The analysis included five distinct groups: White (Branco), Black (Preto), Brown or Mixed-race (Pardo), Yellow/Asian (Amarelo), and Indigenous (Indígena). No grouping of categories was performed; each was examined separately to reflect the full demographic distribution. Given the aggregated and anonymized structure of the dataset, only descriptive analyses were performed.

3 Results

3.1 In this study, HS services refer exclusively to medical consultations coded with ICD-10 L73.2 recorded in the outpatient information system (SIA-PA)

Based on the consultations of individuals with HS in relation to age group and sex (Fig. 1), the largest group was aged between 21 and 30 years. Women had the highest number of consultations than men in almost all age groups. Consultations decreased progressively with age, with a sharp drop after 50 years. The age group of 0 to 10 years had the lowest number of consultations.

By self-reported race/ethnicity (Fig. 2), consultations were more frequent among individuals identifying as white than among those identifying as brown (pardo). We observe that the lowest number of consultations was among black, yellow (Asian), and indigenous individuals, respectively.

Geographically. the distribution of HS-related consultations per 100,000 generais outpatient consultations, (Fig. 3) varied significantly between states and over time. In 2020, we observed a low number of consultations, mainly in the Northern Region of the

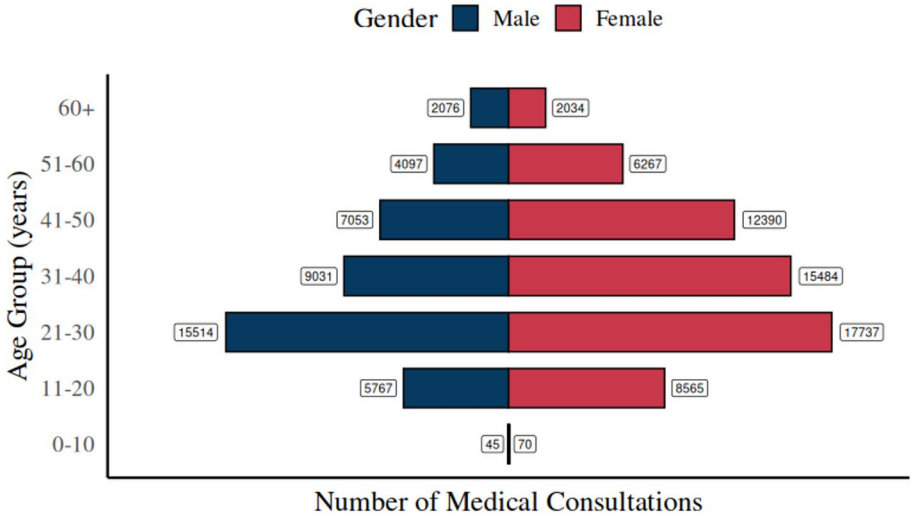

Fig. 1 Demographic medical consultations according to age group and sex (SIA-PA/SUS)

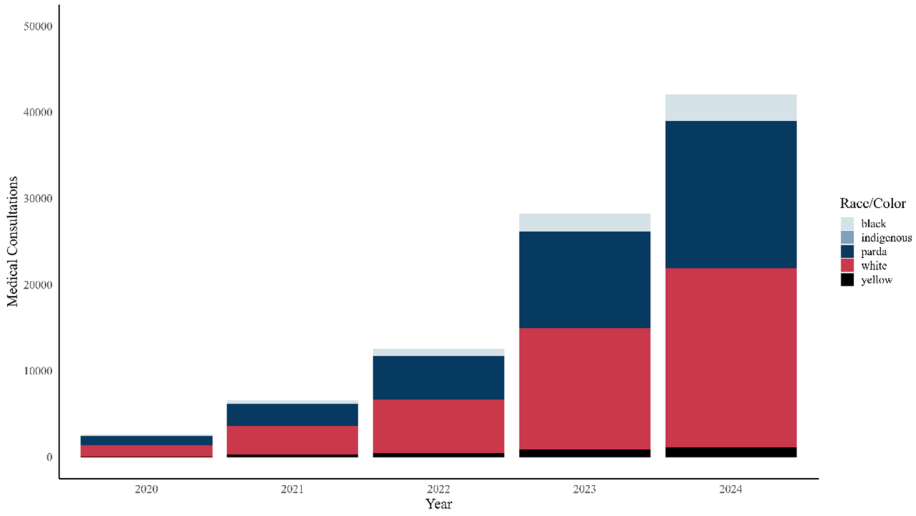

Fig. 2 Number of consultations by race and color (SIA-PA/SUS)

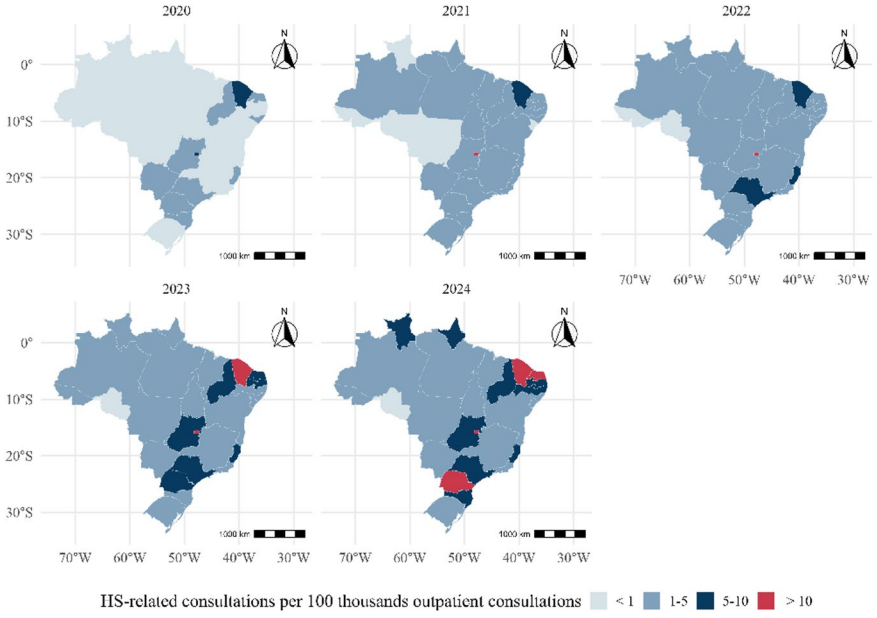

Fig. 3 Geographical Distribution of HS consultations (SIA-PA/SUS)

country. In the following years, from 2021 to 2024, there was an increase, but in 2024, the Federal District, Ceará, Rio Grande do Norte, and Paraná showed a more significant increase, exceeding 10 consultations per 100,000. In contrast, the state of Rondonia remained stable throughout all the analyzed years.

In the analysis of the volume of consultations by state between 2020 and 2024, the state of São Paulo stands out as the absolute leader in volume, with a significant increase in visits from 2020 to 2024. Other states such as Paraná, Minas Gerais, Ceara, and Rio de Janeiro also showed robust and continuous growth. In contrast, states in the North region, such as Roraima, Amapa, and Acre, also recorded progressive growth, despite starting from very low or zero baselines Table 1.

The monthly evolution of the number of consultations from 2020 to 2024 (Fig. 4). A consistent increase in the volume of consultations is observed over the years, with a

Table 1 Number of HS outpatient consultations by state, from 2020 to 2024 (SIA-SUS)

State	2020	2021	2022	2023	2024	State	2020	2021	2022	2023	2024
Acre	-	5	4	13	79	Paraíba	25	145	319	471	828
Alagoas	59	99	144	232	375	Pará	18	163	291	293	562
Amapá	-	12	16	30	76	Pernambuco	32	268	421	714	1127
Amazonas	29	73	135	190	320	Piauí	20	56	92	177	223
Bahia	79	271	509	806	1051	Rio Grande do Norte	34	99	165	503	868
Ceará	425	813	1405	2086	3180	Rio Grande do Sul	289	469	761	1005	1439
Distrito Federal	211	489	858	997	1269	Rio de Janeiro	137	578	1235	2051	3761
Espírito Santo	101	295	434	602	961	Rondônia	6	14	6	15	45
Goiás	281	247	519	859	1259	Roraima	-	-	11	15	30
Maranhão	36	76	160	263	346	Santa Catarina	226	637	1120	1611	2165
Mato Grosso	15	78	178	354	588	Sergipe	18	59	149	247	431
Mato Grosso do Sul	77	158	179	319	395	São Paulo	1688	4636	7093	10124	13398
Minas Gerais	198	726	1380	2022	2606	Tocantins	12	33	51	89	90
Paraná	380	1160	1686	2632	4604						

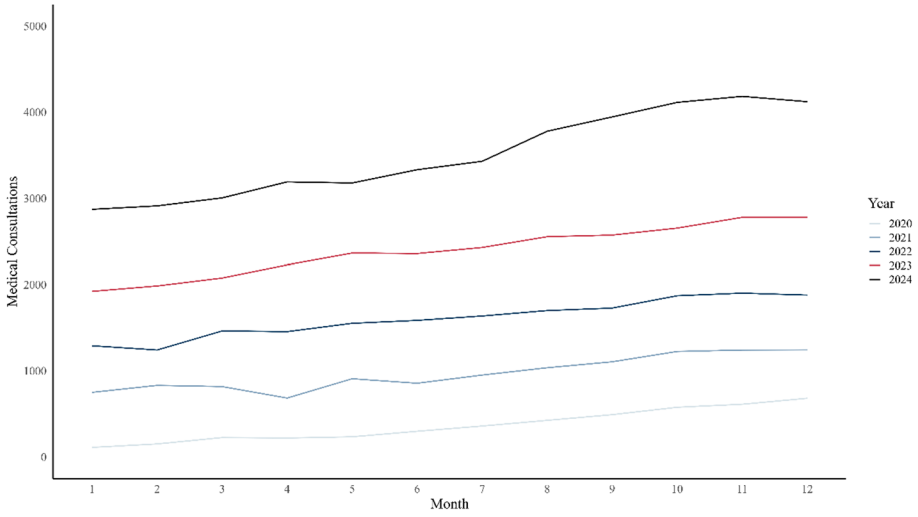

Fig. 4 Monthly evolution of the number of consultations from 2020 to 2024 (SIA-SUS)

trend of growth starting in 2021, reaching the highest number of consultations in 2024. In 2020, the volume was relatively low, but there was a progressive increase in the following months. From 2021, the consultation rate increased sharply, with 2024 standing out as the year with the highest volumes, particularly in the last months. The analysis indicates a progressive stabilization in the monthly volume of consultations, especially in the more recent years.

The analysis of the distribution of the number of appointments performed between 2020 and 2024 (Fig. 5), categorized by classified procedures, according to the System for Managing the Table of Procedures, Medications, Orthoses, Prostheses, and Special Materials (SIGTAP). A significant increase in the number of procedures was observed over the years, with 2024 standing out as having the highest volume. Medication-related appointments were the most frequent and showed steady growth. Clinical procedures also showed an increase, while surgical procedures constituted a smaller and stable portion of the total.

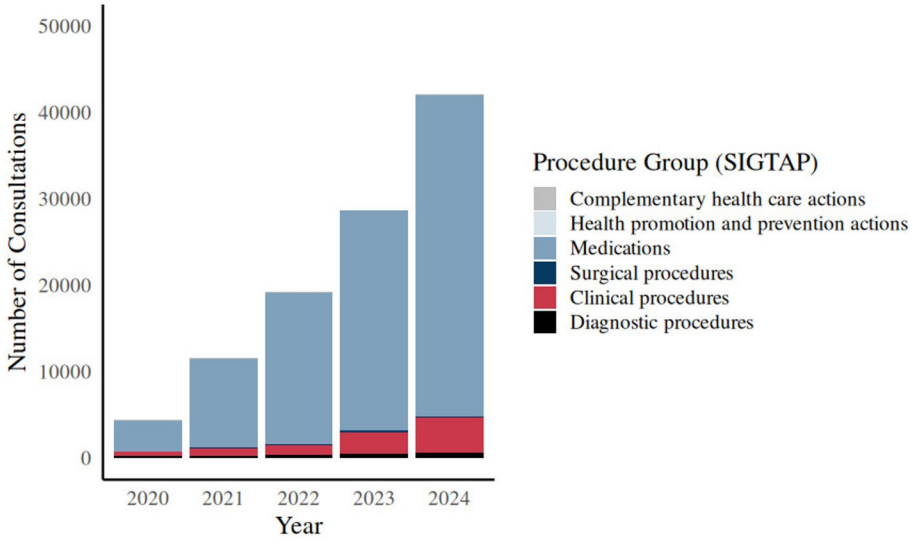

Fig. 5 Distribution of the number of services performed by group according to SIGTAP (SIA-SUS)

Table 2 Annual distribution of the number of procedures registered by codes in SIGTAP (SIA-PA/SUS)

SIGTAP Code	Description	2020	2021	2022	2023	2024
0401010015	Grade II dressing with or without debriment	37	45	50	133	76
0401010058	Excision of lesion and/or suture of skin, appendages and mucosa wound	26	41	65	68	89
0413040011	Flap autonomization	1	-	-	-	-
0417010060	Sedation	1	-	-	1	1
0417010052	Regional anesthesia	-	7	16	24	32

Among the outpatient procedure items for different SIGTAP codes (Table 2), "Grade II dressing with or without debridement" showed a marked increase between 2020 and 2023, followed by a decline in 2024. "Lesion excision and/or suturing of the skin, adnexa, and mucosa" and "Regional anesthesia" exhibited a progressive increase throughout the entire period.

The use of immunobiologicals for HS showed a clear tendency towards shifting from the reference drug (adalimumab) to its biosimilars between 2020 and 2024 (Fig. 6). While the use of the reference drug peaked in 2022 and then declined, the use of biosimilars grew exponentially. Biosimilar A, introduced in 2021, became the most widely used immunobiological in 2024. Overall, the total number of treatments in the adalimumab class (reference and biosimilars combined) increased significantly between 2020 and 2024.

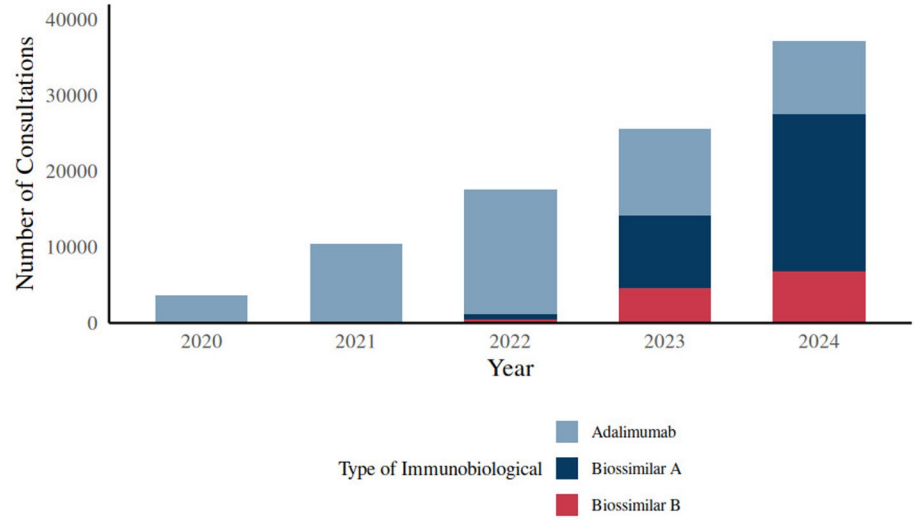

Fig. 6 Annual number of consultation for the treatment of Hidradenitis Suppurativa with Adalimumab (reference) and its biosimilars (A and B) in Brazil (SIA-SUS)

4 Discussion

In order to contextualize the demographic findings of this study, it is relevant to note that, according to the 2022 Census, the Brazilian population is composed of 51.5% women. Regarding race/color, 55.5% of the population is Black (comprising 45.3% Pardo and 10.2% Black), while 43.5% self-identify as White [27]. These demographic data serve as an essential benchmark to analyze the profile of the patients treated and discuss the disparities observed in access to care for Hidradenitis Suppurativa.

4.1 General overview of HS-related consultation and procedures in the public health system

This study provides a comprehensive overview of HS epidemiology in Brazil, focusing on outpatient care within the Unified Health System (SUS) from 2020 to 2024. Through data made available in the SAI-PA by DATASUS, the study shows the demographic landscape of HS.

The profile of HS patients primarily includes young adults between 21 and 30 years of age, with a predominance of females in almost all age groups, except for those aged 0 to 10 years, the number of female consultations exceeded that of males, corroborating epidemiological data that HS is more frequent in women [28–30]. The number of consultations progressively declined with increasing age. Although the 31–40 and 41–50 age groups still presented substantial numbers, a sharp decline was observed after the age of 50, which may reflect hormonal changes, lifestyle shifts, or a lower tendency to seek medical care in this age group. The rarity of cases in children under 10 reinforces the hypothesis of hormonal influence on disease onset, typically after puberty, consistent with global epidemiological data [2, 31, 32].

The predominance of patients self-identified as white represents the vast majority of consultations, followed by Mixed-race (Pardo) and Black individuals, suggesting differences in access to healthcare services or in healthcare-seeking behaviors among racial groups. This may indicate a lower tendency to seek care among Pardo or Black populations, even though the majority of the Brazilian population identifies with these

categories. There are no national data on the prevalence or incidence of HS in these populations. Regarding race/ethnicity, international studies indicate that the prevalence of HS is proportionally higher among Black/African American populations, who also present more severe forms of the disease and a higher number of comorbidities, consequently leading to greater use of healthcare services [33–36]. The data also revealed low representation of Asian and Indigenous individuals, with 2,763 and nine consultations, respectively. Thus, we observe that these low representations of these populations in the extracted data likely reflect structural, geographical, and cultural barriers, as well as underdiagnosis and the systemic invisibility of these populations within the healthcare system [37–39].

Analysis of the geographic distribution of HS-related consultations per 100,000 generais outpatient services in Brazil provides a comprehensive understanding of the spatial and temporal frequency of these consultations across states. These variations may also reflect differences in service infrastructure and population density [30, 40]. The number of health services in 2024 in Ceara, the Federal District, Rio Grande do Norte, and Paraná may indicate an expansion in the supply of specialized services, as well as greater health infrastructure and the presence of specialized medical center in these regions. Furthermore, the study by Jemec and Kimball [32] and Schultheis et al. [41] suggest that the capacity to diagnose HS in regions with better infrastructure contributes to increased early detection, positively impacting prognosis and the patient's perception of care quality, which is reflected in a higher number of consultations.

The number of HS-related outpatient visits per year and month shows a gradual increase over the years, from 2020 to 2024. This trend maybe associated with several factors, including improvements in reporting within the information system, increased awareness of the disease among healthcare professionals and the general population, better diagnostic and treatment conditions, expanded access to specialized services, and the possibility of a real increase in the prevalence and/or incidence of hidradenitis suppurativa [42–48]. Additionally, the monthly fluctuations observed may also be influenced by seasonal patterns in healthcare demand, the periodic availability of medical staff, awareness campaigns related to skin diseases, and administrative factors such o budget cycles or data consolidation delays at the municipal level. These dynamics should be considered when interpreting temporal trends.

The analysis of the types of annual care by groups extracted from SIGTAP revealed notable trends in the management of HS from 2020 to 2024. The predominance of clinical and drug procedures suggests a preference for conservative and outpatient treatment, in line with current health system guidelines and the greater availability of systemic therapies. Consequently, surgical procedures reveal a small fraction of the total care extracted from SIGTAP, which suggests that indications remain restricted to moderate, severe, and refractory cases, following national and international recommendations [30, 47–51]. Regarding clinical procedures, it was observed that diagnostic procedures, complementary health care actions, and health promotion and prevention actions remained with low registration levels over the five years evaluated, which may reflect structural, technological, and organizational limitations, professional initiatives, institutional support, and resources for implementing these practices in the country's public health system. Knowing the importance of these practices can bring health benefits in primary care, it encourages patients to be more active in their own self-care, knowledge about

their condition, improves their quality of life, strengthens the bond with health professionals, and reduces costs for medications and highly complex services [42, 46, 47, 53]. Regarding the annual distribution of procedures recorded by SIGTAP code, the low number of records can be explained by the fact that these procedures are used in moderate to severe cases, when there is significant tissue damage and clinical treatments are no longer effective [51–54]. Furthermore, the low frequency of records may reflect partially completed or missing entries in the system, influenced by factors such as ongoing professional training, challenges in integrating and standardizing data across different services and regions, and limited access to technological infrastructure [57].

The expressive increase in the use of biological therapies, which grew by almost 825% between 2020 and 2024, demonstrates the expansion of access to more advanced options for HS in the SUS. The progressive replacement of reference adalimumab with biosimilars, which now account for 74% of treatments, reflects a strategy for cost containment of up to 30% and greater availability. This rapid shift from the reference biologic to biosimilars, is largely attributable to economic incentives established by the public purchasing system, the expiration of adalimumab's patent, and policies encouraging the adoption of cost-effective biosimilar alternatives. Additionally, logistical aspects such as improved distribution networks and availability in public pharmacies likely contributed to this transition. However, although biosimilars are effective and safe alternatives, the evaluation of their cost-effectiveness and clinical impact in the Brazilian context still requires long-term studies [54–57].

Future studies should prioritize the collection of detailed clinical data and the inclusion of patients from the private healthcare sector to provide a more accurate representation of HS in Brazil. Qualitative research involving Black and Indigenous populations is essential to identify cultural barriers to diagnosis [58–60], and cost-effectiveness analyses can help guide resource allocation for biosimilar therapies [61].

4.2 Study limitations and practical implications

The limitations of this study must be acknowledged. First, only 75% of the population relies exclusively on the SUS, likely resulting in an imprecise estimate of the HS burden among higher socioeconomic groups [62]. Additionally, the absence of detailed data from the private healthcare system limits the understanding of HS in a significant portion of the population. This gap is especially relevant in Brazil, where private health plans are more prevalent among individuals with higher income, potentially leading to an underestimation of total case numbers and differences in access to care. This limitation should be clearly considered when interpreting the epidemiological scope of this study.

Furthermore, the misclassification of ICD-10 code L73.2 is a known issue, given that HS is frequently mistaken for other skin infections such as bacterial abscesses, folliculitis, and furuncles in primary care settings [42, 63]. This miscoding can contribute to both overreporting and underreporting, directly affecting the reliability of prevalence estimates and the accuracy of the analyzed data.

Finally, the inability to anonymize data impedes prevalence analysis, as the same patient may be registered multiple times in separate consultations. These repeated registrations can lead to an overestimation of the number of affected individuals, particularly in chronic diseases such as HS that require multiple outpatient visits. Therefore,

this issue impacts the precision of disease burden estimates and should be explicitly acknowledged in future studies.

Despite these limitations, the results point to practical implications. The fact that most HS cases occur among young women is associated with high rates of depression and anxiety in this demographic group. Therefore, there is a need to integrate psychological care into dermatological services for patients with the disease [64, 65]. To address racial disparities, professional training campaigns in dermatology are necessary, as well as the expansion of healthcare teams in vulnerable and indigenous territories [34, 63, 66, 67]. The significant geographic variation emphasizes the need for regional reference centers capable of offering specialized assistance and treatments, from biological therapies to surgical excision, ensuring equitable and effective access.

Future studies should prioritize the collection of detailed clinical data and the inclusion of patients from the private healthcare sector to provide a more accurate representation of HS in Brazil. Qualitative research involving Black and Indigenous populations is essential to identify cultural barriers to diagnosis [57–59], and cost-effectiveness analyses can help guide resource allocation for biosimilar therapies [60, 61].

5 Conclusions

When analyzing the temporal and geographic data on outpatient care, we see a progressive and significant increase in the number of HS-related cases registered in the SUS. These data cover the period between 2020 and 2024, revealing a continued increase in demand for services, significant demographic and geographic disparities, and a rapid transition to the use of biosimilar therapies. Our findings highlight the growing epidemiological burden of HS and reinforce the urgent need for targeted public policies to reduce inequalities and ensure equitable access to diagnosis and treatment for all patients in the country.

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Author contributions

Conceptualization: N.P.S, R.R.M., and B.A.S.; Methodology: R.R.M and N.P.S.; Formal Analysis: N.P.S., R.R.M., B.A.S., L.A.C.B., H.R.D. and S.C; Investigation: N.P.S., R.R.M., B.A.S; Resources: N.P.S, R.R.M., and B.A.S.; Data Curation: N.P.S.,B.A.S. and H.R.D; Writing – Original Draft Preparation: N.P.S; Writing – Review & Editing: N.P.S., B.A.S. and H.R.D .; Visualization: N.P.S, R.R.M.; Supervision: R.R.M., L.A.C.B and S.C.; Project Administration: L.A.C.B. and and S.C.; Funding Acquisition: L.A.C.B and S.C.

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Data availability

The datasets used for data processing and analysis is available from the corresponding author upon request.

Declarations

Ethics approval and consent to participate

This study was based exclusively on secondary, publicly available, and anonymized data obtained from the Department of Informatics of the Unified Health System (DATASUS). The research utilized information in the public domain that does not allow for the individual identification of participants, therefore ethical approval by a Research Ethics Committee was not required.

Consent for publication

Not applicable.

Competing interests
The authors declare no competing interests.

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