



Navigating the Multidimensional Impact of Living with Hidradenitis Suppurativa: An In-Depth Netnographic Study on Social Media Platforms

Ericles Andrei Bellei · André Vicente Esteves de Carvalho ·
Beatriz Magalhães Eng · Carla Tozato · Danilo Hamilko de Barros ·
Erika Yumi Tamashiro · Gleison Vieira Duarte · Rafael Toledo Rodrigues de Fátima ·
Renata Ferreira Magalhães · Roberto Souto da Silva · Wagner Guimarães Galvão Cesar ·
Felipe Garutti Thies

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ABSTRACT

Introduction: Hidradenitis suppurativa (HS) is a chronic skin condition causing considerable distress. It impacts mobility, social interaction, and quality of life. In Brazil, there is a notable gap in epidemiological data and patient experiences regarding HS.

Methods: This study, spanning 2019 to 2022, employed netnography to probe the experiences of Brazilian patients with HS. This

approach gleans insights from online interactions, offering a direct view into patients' lives.

Results: Notably, the data illuminated the challenges patients face, such as difficulties in obtaining a diagnosis and the complexities involved in managing a chronic, and often debilitating, condition. Furthermore, patients' experiences with various treatments, encompassing antibiotics, biologic agents, lifestyle alterations, surgical procedures, and alternative remedies, were also examined.

Conclusion: By undertaking a longitudinal analysis of patient interactions, the study aimed to offer a richer understanding of HS, from its diagnosis to its treatment. It underscores the

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E. A. Bellei (✉) · R. T. R. de Fátima
Department of Data, Digital, and Innovation,
Novartis, São Paulo, Brazil
e-mail: ericles_bellei@hotmail.com

A. V. E. de Carvalho
Hospital Moinhos de Ventos de Porto Alegre, Porto
Alegre, Brazil

B. M. Eng
Patient Support Program, Novartis, São Paulo, Brazil

C. Tozato
Value and Access Division, Novartis, São Paulo,
Brazil

D. H. de Barros
Dermatology Service, Hospital Irmandade Santa
Casa de Curitiba, Curitiba, Brazil

E. Y. Tamashiro · F. G. Thies
Immunology Franchise, Novartis, São Paulo, Brazil

G. V. Duarte
Instituto Bahiano de Imunoterapia (IBIS), Salvador,
Brazil

R. F. Magalhães
School of Medical Sciences, State University of
Campinas (UNICAMP), Campinas, Brazil

R. S. da Silva
Department of Dermatology, Rio de Janeiro State
University (UERJ), Rio de Janeiro, Brazil

W. G. G. Cesar
Hospital Alemão Oswaldo Cruz, São Paulo, Brazil

necessity for a more patient-centered approach when managing this condition. We hope that this enhanced understanding can facilitate better care for those affected by HS.

Keywords: Hidradenitis suppurativa; Quality of life; Global burden of disease; Social media; Patient satisfaction; Healthcare innovation

Key Summary Points

Why carry out this study?

Hidradenitis suppurativa (HS) is a multifaceted disease with profound impacts on patients' lives, from the physical symptoms to the psychosocial effects. The study sought to delve into the patient experiences, emphasizing their reported symptoms, treatment preferences, and the overall quality of life with HS, highlighting areas that require improved awareness and understanding within the medical community.

What was learned from this study?

A significant number of patients with HS face challenges such as misdiagnosis and resort to self-diagnosis. There is also a notable inclination towards alternative treatments. These findings stress the importance of an integrated, patient-centered approach to HS care, one that prioritizes timely diagnosis, holistic treatment, and psychosocial support.

The study illuminated the pressing need for improved professional awareness and patient–doctor communication in the realm of HS care and treatment.

INTRODUCTION

Hidradenitis suppurativa (HS) is a chronic inflammatory skin disease that has been associated with profound physical and psychological distress [1–3]. The etiology of HS is

multifaceted, encompassing genetic predisposition, hormonal imbalances, and immune system responses that lead to hair follicle inflammation [4, 5]. Characterized by recurrent painful nodules, abscesses, draining/not draining sinus tracts and hypertrophic scars primarily in areas rich in apocrine glands, HS affects approximately 0.05–4.1% of the global population [6–8]. However, the disease's prevalence belies the depth and complexity of the lived experiences of those affected, which can encompass physical discomfort, emotional distress, and significant social difficulties [9, 10]. The impacts are not merely skin-deep, but infiltrate daily life, shaping patients' perceptions of self and others, affecting their relationships and participation in social activities, and challenging their mental and emotional resilience [11].

Despite the global reach of HS, the understanding of the disease within the Brazilian context remains limited. The condition is more prevalent in women, appearing twice as often as in men, and typically impacts individuals aged between 18 and 44 years. In Brazil, about 0.41% of the population has the disease, with an average age of around 40 years. Interestingly, the disease is more common in teenagers (0.57%) and adults (0.47%) [8]. HS presents a unique set of challenges for patients in Brazil, a diverse country characterized by vast regional differences in healthcare access and quality, socioeconomic disparities, and cultural beliefs and practices related to health and illness [12, 13]. Previous studies on HS in Brazil have primarily focused on clinical aspects such as disease prevalence, symptomatology, and treatment modalities, thereby leaving a gap in understanding the lived experiences of patients [8, 12, 14, 15].

The salience of understanding patients' lived experiences of HS is underscored by the increasing recognition of the centrality of patient experience in healthcare. The patient's viewpoint is simply a side element in healthcare but rather an essential part of patient-focused care and creating health policies [16, 17]. It is crucial to gain insights into patients' experiences of their symptoms, their interactions with healthcare providers, their coping strategies,

and their perceived needs [18]. As online communications among patients with HS may reflect community needs [19], we have adopted the approach of netnography, a research method that harnesses the power of the digital age to examine naturally occurring data from online communities and social media platforms [20, 21], where dermatological concerns have seen a significant rise [22–24]. Netnography offers a valuable approach for health research by analyzing patient interactions and behavior online. This method enables the collection and analysis of data from online communities and social networks, providing insights into patients' experiences and perspectives on health-related topics [25].

The present study illuminates the experiences of Brazilian patients with HS, their emotional well-being, and the disease's impact on their daily lives. Additionally, it explores their healthcare journey, from the challenges of getting a diagnosis to the ups and downs of living with a chronic, often debilitating condition. Our netnographic study also provides insight into the experiences of Brazilian patients with HS with different treatment options. We investigate their experiences with drug treatments, from antibiotics to biologic agents, as well as non-drug approaches like lifestyle changes, surgical procedures and alternative treatments, an area in HS that has not been extensively researched [26]. This study of the experiences of Brazilian patients with HS aims to enhance knowledge about HS in Brazil, inform healthcare practices, and shape policies to better address patients' needs.

METHODS

Research Planning, Entrée, and Data Collection

The primary aim of this research was to enhance the understanding of the key aspects important to patients with HS by gaining spontaneous insights into their perceptions regarding symptoms, diagnosis, treatments, experiences with healthcare professionals, the healthcare system, and the impact on their quality of life. Various

data collection strategies were implemented to identify channels and periods with significant content production on social media platforms, revealing online conversations and patient behaviors. This involved identifying individuals (patients, physicians, other healthcare professionals) and organizations (medical associations, patient advocacy groups, clinics) that serve as hubs for generating strategic content. These strategies were employed for analysis, as patient reports are commonly found in the posts. The following strategies were utilized:

- Consensus-based definition of keywords and search strategies by healthcare professionals experienced in HS and researchers experienced in netnography
- Identification and mapping of awareness dates related to the pathology at local, national, or international levels
- Identification and mapping of events focused on the topic, including those targeting patients or healthcare professionals
- Identification and mapping of influential patients, patient associations, entities, non-governmental organizations, and other institutions providing support to patients with this pathology
- Identification and mapping of doctors, healthcare professionals, medical associations, and clinics specialized in treating this pathology

Data extraction was performed at the beginning of 2023 considering the period from January 1, 2019 to December 31, 2022. Throughout the data collection, original user-generated publications on social networks were identified. These publications served as valuable sources of narratives, providing a context to qualify the comments and responses found within them. This approach proved instrumental in expanding and enhancing the collection of reports from patients and caregivers, including those who may not directly share on their personal social media accounts but actively engage in the ongoing discussions.

Distinct methodologies were implemented for each social network platform, taking into consideration their unique parameters (Table 1). The filter for Brazilian users is based

Table 1 Data collected and analyzed per platform

Platform	Collection parameter (posts in Brazil)	Number of posts	Number of narratives collected	Narratives analyzed after qualifying filters
Instagram	Posts with #hidradenitissuppurativa (Portuguese equivalent) and all its comments	217	4052	651
YouTube	Videos about HS (all comments)	103	5350	2351
Facebook	Publications about HS in Brazilian pages and public groups (all comments)	86	543	98
Twitter	Tweets mentioning (Portuguese equivalents) “Hidradenitis suppurativa”, “Adalimumab”; replies to classified tweets	Uncountable	3456	752
TikTok	Patient videos about HS (all comments)	10	1498	577
Total		416	14,899	4429

on the social network’s algorithm, which inherently selects for Brazilian Portuguese, and utilized search parameters when available. Subsequently, a qualitative categorization was conducted, excluding publications that lacked associated comments or fell outside the scope of interest. All user-generated units of information within social media platforms, including posts, comments, and responses, were collected as “narratives.” Following this, a secondary manual qualitative filter was applied to eliminate narratives lacking semantic value, duplicates, or those not aligned with the designated theme. Ultimately, a curated collection of qualified narratives was obtained, from which various metadata categories were extracted and classified, forming the foundation of the study’s database.

Data Clustering and Analysis

From the conciliation of points of interest of the research and the methodology of data collection and classification, the initial scope was developed from four qualitative categories of analysis:

1. “HS symptomatology and manifestations”: Primary physical symptoms experienced by patients (pain, inflammation, nodules, etc.) and associated emotional symptoms (depression, anxiety, distress, etc.).
2. “Quality of life of patients with HS”: Examination of social, psychological, leisure, occupational, and lifestyle-related impacts on patients’ quality of life, encompassing areas such as social interactions, family relationships, and personal relationships.
3. “Patient journey”: Exploration of the steps taken by patients from symptom recognition to seeking medical assistance, including encounters with different medical specialties, experiences of misdiagnosis, the number of healthcare providers consulted, and the pathway to accurate diagnosis and disease management.
4. “Treatment approaches and patient perspectives in HS”: Investigation of the main treatment modalities utilized by patients and the satisfaction or dissatisfaction associated with these treatments, along with an examination of the factors contributing to these sentiments. This category includes pharmacological interventions (oral, topical, or injectable) as well as non-pharmacological approaches. Additionally, alternative treatments such as surgical interventions, drainage procedures, and

unconventional therapies like hemotherapy, ozone therapy, and microphysiotherapy are encompassed in a separate category.

Data were analyzed with natural language processing techniques that involved encoding conversion to ASCII; trimming; removal of emojis and stopwords; lemmatization and tokenization based on an open-source model of Brazilian Portuguese (Stanza model), calculation of relevance of terms (scaled f-score), and generation of processed corpus from pre-processed comments compared to a standard corpus (Spacy). The Tree Intelligence LivingStakeholders tool and libraries in Python language were used.

Ethical Considerations

All data was collected and initially analyzed by an external consulting agency (Tree Intelligence). All the data collected, analyzed, and presented in this study were exclusively sourced from public and openly accessible platforms. No information was obtained from password-protected sources or by connecting to closed social media profiles, such as Facebook groups for patients with HS, to gather research-relevant information. To fully protect the privacy and identity of patients and other individuals, the narratives were anonymized. This article underwent review by the scientific committee of Novartis (code CLR-12165/AIN-MS-117664) and was approved for publication without requiring an additional review by an ethics committee.

RESULTS

Table 2 presents the analysis of 4429 narratives collected from various social media platforms between 2019 and 2022. YouTube and Twitter were the primary sources, contributing 53% and 17% of the qualified narratives, respectively. The data show a progressive increase in narratives over the years, with a peak in 2021, driven by significant events and viral posts. The majority of narratives, 92.4% of the sample, came from patients, while caregivers and

individuals identified as both patient and caregiver accounted for 7.3% and 0.3%, respectively. Among single users, female users predominated in both the patient (78%) and caregiver (90.7%) groups. The table also highlights the key themes discussed in the narratives. “Patient’s journey” and “understanding about HS” emerged as the most prevalent topics, accounting for 58% and 51.6% of the narratives, respectively. Other topics such as “treatment” and “quality of life” were also frequently mentioned.

HS Symptomatology and Manifestations

Among the 1326 narratives discussing HS symptoms (Fig. 1) and affected body areas (Fig. 2), typically containing more than one symptom per narrative, pain (45.2%) and inflammation (12.8%) were the most mentioned, followed by lump (9.6%) and lesion (6%). Terms such as pus, nodule and cicatrization, furuncle, and odor were also indicative of similar symptoms. Out of the 4429 narratives, 845 (19%) specified the affected body regions associated with HS. Typically, patients mentioned multiple regions in a single narrative. In women, the most affected areas were the armpits, arms, groin, breasts, and buttocks. In men, the gluteal regions, armpits, and groin were most frequently cited. Among the narratives, HS severity levels were identified for 79 patients. Stage 3 HS was the most reported, mentioned by 44 patients (55.6% of the total reported grades). Stage 2 was reported by 16 patients, while stage 1 was mentioned by 18 patients.

Among the 4429 narratives, 15.6% of them mentioned various factors that aggravate HS (Fig. 3), encompassing 25 different types. The most frequently cited factors were related to diet (31.6% of mentions), followed by depilation (16.2%), use of deodorant (14.7%), and psychological/emotional issues (8.2%). Weight gain and obesity accounted for 6.2% of mentions, while smoking was cited in 3.1% of cases. Interestingly, there were counternarratives in which patients who were not overweight or did not smoke still experienced HS. In women, the menstrual period (6.2%) and pregnancy (5.4%)

Table 2 Summary of type of data collected from narratives about HS on social media in Brazil (2019–2022)

Category	Number	Percent
Source platform		
YouTube	2351	53.0
Twitter	752	17.0
Instagram	651	14.7
TikTok	577	13.0
Facebook	98	2.2
Year of publication		
2019	568	12.8
2020	1035	23.3
2021	1589	35.8
2022	1236	27.9
Origin of the narrative		
Patient	4093	92.4
Caregiver	324	7.3
Both	12	0.3
Unique users		
Patient	2514	91.7
Caregiver	225	8.2
Both	3	0.1
Age category		
Child: up to 14 years	19	0.7
Adolescent: 15–19 years	60	2.2
Young adult: 20–29 years	263	9.6
Adult: 30–59 years	285	10.4
Elderly: over 60 years	6	0.2
Unidentified	2110	76.9
Unique users region of Brazil		
Southeast	181	6.6
Northeast	57	2.0
South	22	0.8
Central-west	16	0.6
North	6	0.2

Table 2 continued

Category	Number	Percent
Unidentified	2460	89.7
Narrative topics		
Patient journey	2570	58.0
Symptomatology and manifestations	2284	51.6
Treatment approaches	1811	40.9
Quality of life	912	20.6
Number of themes mentioned in the narratives		
1	2077	46.8
2	1650	37.2
3	604	13.6
4	98	2.2

were also reported as exacerbating factors. Comorbidities frequently mentioned in patients with HS include diabetes (15 mentions), gastrointestinal diseases (6 mentions), and psoriasis (6 mentions). Other comorbidities were mentioned less frequently, including COVID-19 (5 mentions), arthritis (4 mentions), pilonidal cyst (4 mentions), hypothyroidism (5 mentions), lupus (3 mentions), polycystic ovary syndrome (4 mentions), Down syndrome (3 mentions), autism (2 mentions), cancer (2 mentions), Crohn's disease (2 mentions), fibromyalgia (2 mentions), ADHD (2 mentions), and vitiligo (2 mentions).

Quality of Life of Patients with HS

In the psychological analysis (Fig. 4) of 775 narratives from patients with HS, predominant emotions were identified. Sadness (18.2%) and suffering (16.9%) emerged as the most prevalent feelings. Stigma, shame, and frustration each accounted for 12% of the total, highlighting the emotional challenges experienced. Other

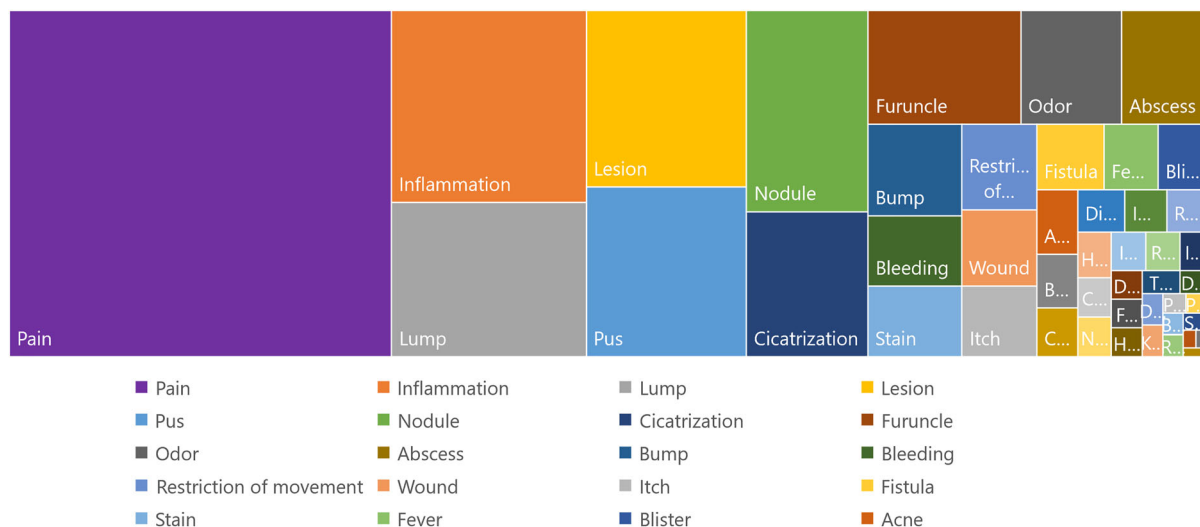


Fig. 1 Symptoms reported in 1326 narratives

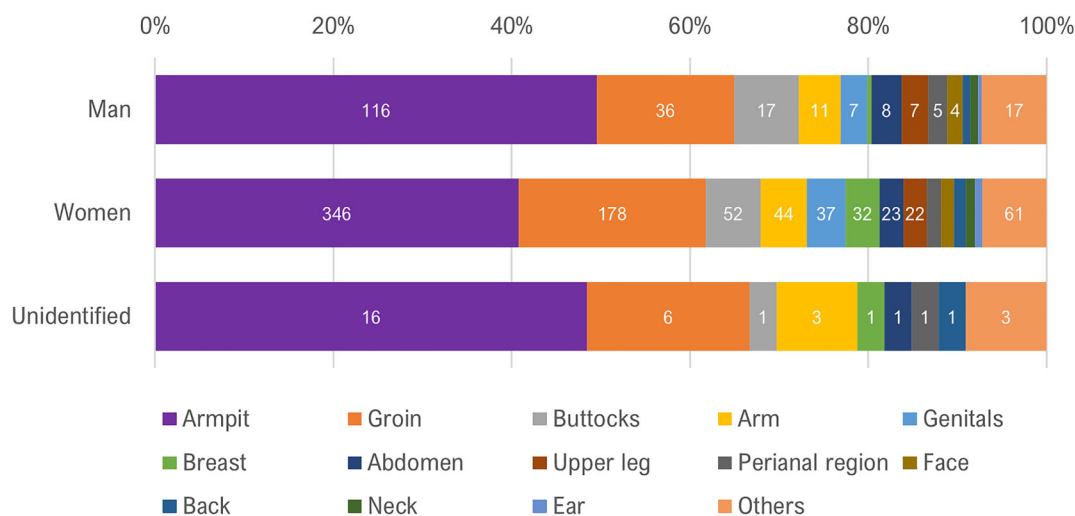


Fig. 2 Affected body areas reported in 845 narratives

emotions reported included low self-esteem (8.9%), fear and insecurity (6.9%), depression (6.2%), suicidal ideation (2.9%), and anxiety (2.1%), demonstrating the broad range of emotional impacts associated with HS. These reactions are understandable, given that the skin, as the largest and most visible organ, significantly influences interpersonal relationships and self-image perception.

In the analysis of the social impacts of HS based on 150 narratives (Fig. 5), various effects were observed. Loss of productivity (24%) and

lifestyle changes (22.8%), including alterations in location, clothing, and diet, were commonly reported. The influence on physical exercise was mentioned minimally (1.6%). HS had significant effects on the work environment (18.4%), leading to embarrassment due to odors and suppurations, absences from work, and difficulties in job searching. Social isolation (19.2%) and impacts on sex life (2%) and romantic relationships (1.2%) were notable. The unpredictable nature of the disease (7.2%) interfered with daily activities. Despite the interpersonal

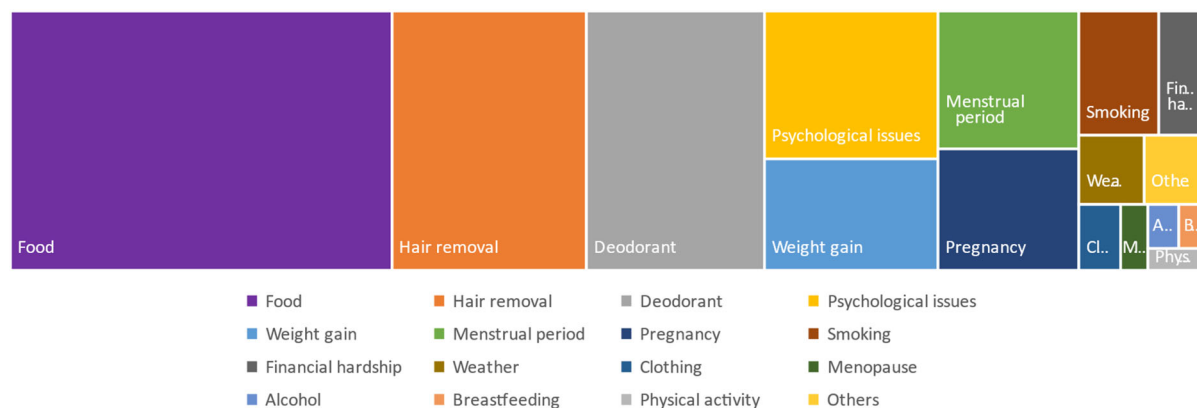


Fig. 3 Exacerbating factors reported in 691 narratives

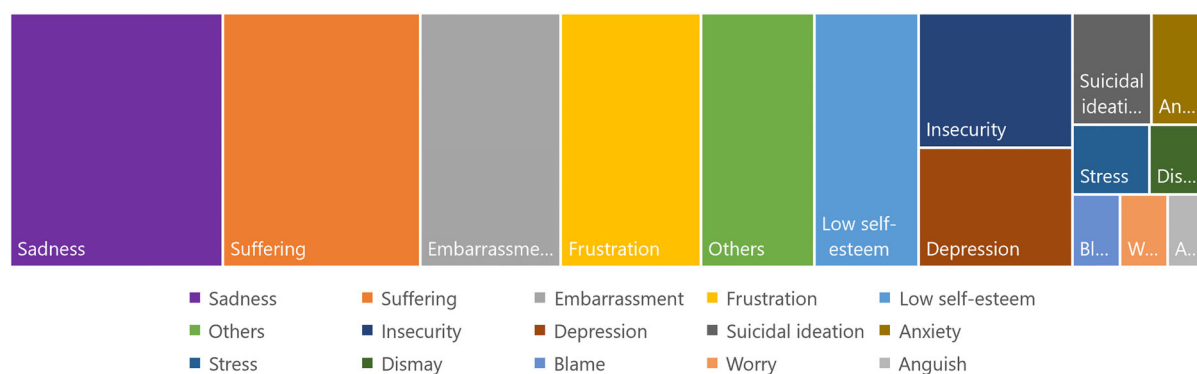


Fig. 4 Identified emotional or psychological impacts for patients with HS; based in 775 narratives

challenges, there was a strong sense of community and empathy among patients, expressed through messages of support and solidarity. Comments such as “we’re together” and “I’m not the only one” reinforced this feeling of togetherness.

Emoji frequency (Fig. 5) is another resource to analyze the most prevalent feelings within the narratives, since they directly express optimistic, neutral, and pessimistic feelings within a context. In Fig. 6, the colors indicate emojis with positive context (green, showing feelings of hope, support, and faith, representing 39% of the total occurrence) and negative context (orange, showing feelings of sadness, crying and distress, representing 53.5% of the total). Another 7.5% of emojis are neutral.

Patient Journey

Table 3 summarizes the narratives about the patient journey. Diagnosis reports totaled 1003 mentions, 76% of which were diagnosed by professionals and 24% were self-diagnosis. The duration of symptoms was mentioned in 499 narratives, corresponding to 11.3% of the general total. Of these, 28.6% of the patients have lived with the symptoms for 15 years or more. A total of 1019 uncertainties were identified in 22.4% of the narratives, categorized into 10 groups. Most inquiries (49.3% of mentions) revolved around HS treatment. Health professionals were mentioned in 341 narratives, accounting for 7.6% of the total. Among these mentions, dermatologists were the most frequently visited professionals, representing 79.2% of them. However, the difficulty in finding professionals prepared to diagnose,

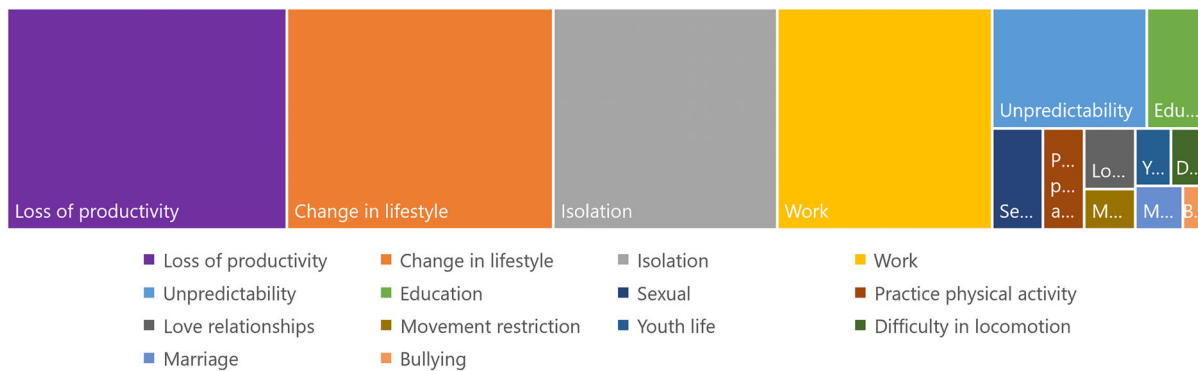


Fig. 5 Identified impacts on the social life of patients with HS; based in 150 narratives

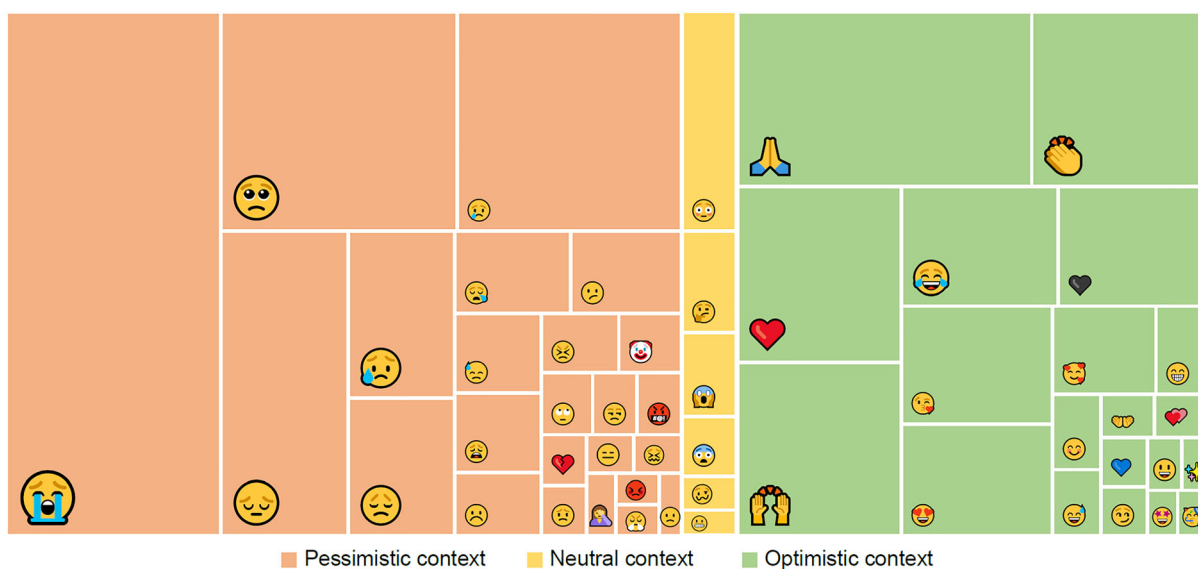


Fig. 6 Emoji frequency analysis based in 1372 occurrences

treat, and monitor HS was expressed in 230 narratives, representing 5.2% of the global total. Nevertheless, incorrect diagnoses were mentioned in 58 reports, or 1.3% of the total, with the diagnoses of furuncles and folliculitis being the most common.

Mentions of visits to the emergency room and hospitalizations represented 0.5% and 0.4% of the total, respectively. There was significant interest in information about surgery for HS, cited in 11% of the narratives. In addition, 7.2% of the narratives mentioned having had one or more surgeries due to HS, with 69% of these patients having undergone a single surgical procedure.

Treatment Approaches and Patient Perspectives in HS

Alternative Approaches

A total of 731 reports (16.5% of the total) identified 153 different approaches to mitigate HS, including practices and restrictions. Oral and topical methods, as well as preventive practices, were notable. Among the oral approaches, 65 reports (8.9% of the subtotal) emphasized the continuous use of alternative foods and supplements. Saffron (24.6% of the subtotal) was the most commonly mentioned, mainly for its anti-inflammatory properties. Vitamin supplementation, specific fruits, teas,

Table 3 Summary of narratives about patient journey on social media in Brazil (2019–2022)

Category	Mentions	% of subtotal	% of total
Who diagnosed	1003		22.6
Health professional	763	76	
Self-diagnosis	240	24	
How long have they had symptoms	499		11.3
15 years or more	143	28.6	
11–14 years	58		
7–10 years	72		
3–6 years	101		
Less than 3 years	125	25	
Uncertainties faced about the HS	1019		22.4
About the treatment	503	49.3	
About the symptoms/ characteristics	164	16	
About the diagnosis	125	12.2	
What specialty to look for	50	4.9	
Surgery	46	4.5	
Treatment access	41	4.0	
Diet	31	3.0	
Prevention	28	2.7	
Updates	16	1.6	
Patient's rights and disability benefits	15	1.5	
Which specialist has been visited	379		7.6
Dermatologist	270	79.2	
Surgeons and plastic surgeons	32	9.4	
Nutritionists/dietitians	15	4.4	
Generalist	10		
Infectologist	9		

Table 3 continued

Category	Mentions	% of subtotal	% of total
Gynecologist	8		
Proctologist	6		
Others	29		
Incorrect diagnosis received	58		1.3
Furuncles/furunculosis	20	34.5	
Folliculitis	10	17.2	
Atopic dermatitis	5		
Others	23		
Surgeries received	321		7.2
Single surgical procedure	221	69	
Multiple or unspecified	100	31	
Mentions about struggling to find a specialist	230		5.2
Mentions about emergency room visits	24		0.5
Mentions of hospitalization	16		0.4
Mentions about seeking surgery	489		11

phytotherapies, and probiotics were also mentioned. Regarding topical medications, 114 reports (15.6% of the subtotal) described the continuous use of specific products with medicinal or palliative properties (45.6% of the subtotal). Hygiene practices for affected areas (28.9% of the subtotal), specific or alternative deodorants (16.7% of the subtotal), and the use of compresses (8.8% of the subtotal) were also mentioned.

The most frequently mentioned specific products were milk of magnesia (21.1% of the subtotal), followed by melaleuca (11.5% of the subtotal) and aloe vera (9.6% of the subtotal).

Other mentioned products included hydrogen peroxide, hot water, clove-infused alcohol, manioc flour, saline solution, talc, lemon, tobacco, baby diaper rash ointment, honey, toothpaste, bathroom disinfectant, vinegar, and unspecified ointments. In terms of hygiene practices, antiseptic soap (42.4% of the subtotal) and coconut soap (12.1% of the subtotal) were the most cited. Specific deodorants and compresses with particular ingredients (chamomile, water with salt, *Libidibia ferrea*, vinegar) or warm applications were also mentioned.

Behaviors, Practices, and Habits

Out of the 550 narratives (12.4% of the total) discussing HS prevention practices, several key categories emerged: dietary restrictions, bathing practices, shaving methods, dressings, activities and special care, and the use of deodorant. Dietary restrictions (199 reports, 36.1% of the subtotal) included avoiding milk/lactose/derivatives (61), gluten (33), sweets/sugar (32), pork (12), fatty foods (10), and carbohydrates (10). Other mentioned items were sausages, animal foods, seafood, alcoholic beverages, wheat, peppers, and spices. Specific diets (175 reports) primarily involved adopting a more natural/healthy/restricted diet (147), general care with food (10), and hydration (5).

Specific activities and care (86 reports, 15.6% of the subtotal) encompassed physical activities (28), psychological/emotional care (12), weight loss (11), and wearing specific clothing (11). Additional mentions included avoiding smoking, excessive sweating, certain contraceptives, exfoliation, and using razors for shaving. Bathing practices (4 reports) mentioned sunbathing, cold baths, and homemade baths. Dressings were rarely mentioned (3 reports), with references to common dressings, scar treatment, and diapers. Practices involving deodorants (42 reports) generally revolved around discontinuing deodorant use altogether (26). Others mentioned avoiding specific brands or formulations (12) or ingredients such as aluminum or lead (4). The most frequently mentioned method of depilation (41 reports, 7.4% of the subtotal) was laser hair removal (33), while waxing (4) and razors (2) were also mentioned.

Drug Therapies

Table 4 presents an analysis of oral medications discussed in a dataset of 201 narratives. Antibiotics were the most frequently mentioned drug class, with a total of 97 occurrences, encompassing various specific drugs such as cephalixin, tetracycline, and amoxicillin. Retinoids, specifically isotretinoin, were the second most cited class, with 59 references. Other drug classes, including non-steroidal anti-inflammatory drugs, antidiabetics, antiparasitic, corticosteroids, contraceptives, and anti-androgens, accounted for 45 occurrences.

Table 5 presents a summary of the key findings related to different topical drugs. The most frequent class is antifungal and antibiotic drugs, accounting for 28 occurrences. Antibiotics combined with anti-inflammatory agents follow closely behind with a total of 27 instances. Other notable classes include antibacterial, enzymatic, and anti-inflammatory drugs, with occurrence counts ranging from 2 to 7. This comprehensive overview showcases the variety of drug classes and their respective frequencies in the dataset. Table 6 provides an overview of the injectable drug distribution, emphasizing the dominance of biologicals and antibiotics.

Non-drug Therapies

Among the non-pharmaceutical oral interventions (60 reports, 26.4% of the subtotal of non-pharmaceutical interventions), saffron (which is also used topically and orally for both treatment and prevention) was the most mentioned (10 mentions), followed by zinc (4 mentions) and vitamin D (3 mentions). Other items mentioned with one or two mentions each are related to supplements and natural remedies, teas and infusions, and natural products. In the category of supplements and natural remedies, we have items such as magnesium chloride, methylcobalamin, vitamin A, betaine, resveratrol, and iodine-containing vitamin. The category of teas and infusions includes burdock tea, ginger tea, panacea tea, and natural tea. Finally, there is the category of natural products, which encompasses a variety of items, such as saffron + lemon, yam elixir, Garrafada (white wine + *Smilax aspera* + *Bauhinia forficata*), iodine, mineral miracle solution, salsa 3 quinas,

Table 4 Summary of 201 narratives mentioning oral drugs

Drug class	Number	Percent	Specific drug or combination (<i>n</i>)
Antibiotics	97	48.3	Cefalexin (22), tetracycline (20), sulfamethoxazole + trimethoprim (12), clindamycin (11), amoxicillin (7), doxycycline (7), ciprofloxacin (6), azithromycin (4), diaminodiphenyl sulfone (5), ampicillin (2), lymecycline (1)
Retinoids	59	29.4	Isotretinoin (59)
NSAIDs	16	8.0	Ibuprofen (10), nimesulide (4), ketoprofen (2)
Antidiabetics	12	6.0	Metformin (12)
Contraceptives	4	2.0	Drospirenone + ethinylestradiol (3), ethinylestradiol + cyproterone (1)
Antiandrogens	3	1.0	Spironolactone (3)
Analgesic	2	1.0	Dipyron (1 g), acetaminophen (1)
Antiparasitics	2	1.0	Ivermectin (2)
Corticosteroids	2	1.0	Prednisone (2)
Others	4	2.0	Others (4)

Table 5 Summary of 122 narratives mentioning topical drugs

Drug class	Number	Percent	Specific drug or combination (<i>n</i>)
Antibiotic and anti-inflammatory	27	22.1	Bacitracin + neomycin (18), betamethasone + gentamicin (9)
Antifungal and antibiotic	28	23.0	Nystatin + zinc oxide (20), nystatin (8)
Anti-inflammatory	10	8.2	Betamethasone (4), mucopolysaccharide polysulfate (4), dexamethasone (2)
Antibiotic	8	6.6	Mupirocin (8)
Antifungal, anti-inflammatory, and antibiotic	8	6.6	Ketoconazole + betamethasone + neomycin (8)
Antibacterial	7	5.7	Fusidic acid (7)
Enzymatic	7	5.7	Collagenase (7)
Vitamin and antibacterial	5	4.1	Vitamin A + triclosan + panthenol (5)
Antibiotic and anti-inflammatory	3	2.5	Sodium sulfacetamide + trolamine (3)
Anti-acne	4	3.3	Benzoyl peroxide (2), benzoyl peroxide + adapalene (2)
Antiseptic	2	1.6	Potassium permanganate (2)
Others	13	10.7	Others (13)

Table 6 Summary of 122 narratives mentioning injectable drugs

Injectable drug	Number	Percent
Adalimumab	187	72.2
Benzathine benzylpenicillin	29	11.2
Unspecified injection	25	9.7
Penicillin	5	1.9
Triamcinolone hexacetonide	3	1.2
Ceftriaxone	2	0.8
Vedolizumab	2	0.8
Morphine	2	0.8
Others	4	1.5

garlic, barbatimão, turmeric, American elixir, galenogal, ginger, and probiotic.

Among the non-pharmaceutical topical interventions (167 reports), Minancora[®] ointment (benzalkonium chloride + zinc oxide + camphor) appears as the most mentioned (16 times), followed by milk of magnesia (12 mentions) and aloe vera (7 mentions). In lesser frequency, a variety of substances used as alternative topicals are also mentioned. In the category of foods and ingredients, there were mentions of garlic, saffron, saffron with honey, red onion, lemon, honey, vinegar, lemon water, saltwater, alcohol with lemon peel. For skin care and wound healing products, we have clay, deep moisturizer, Cicatricure[®], natural ointment, rosehip oil, and zinc oxide. For hygiene care, there are options such as toothpaste, antibacterial soap, antiseptic soap, neutral soap, aroeira soap, glycerin soap, sulfur soap, coconut soap, saline solution, antiseptic spray, antiseptic talcum powder, hydrogen peroxide, and even veterinary healing larvicide. In the category of natural products and plant extracts, we find elements such as chamomile, lavender, tea tree, frankincense, jade plant, pepper leaf, *Stryphnodendron adstringens*, enzymatic cleaner, cat's claw, propolis, andiroba oil, ozonized sunflower oil, and essential oil.

Procedures

Among the procedures mentioned in 404 reports (23.7% of the subtotal), surgery is the most mentioned treatment (224 mentions), both by patients who have undergone the procedure and those seeking information to undergo it. Other mentioned procedures include drainage (26 mentions), laser hair removal (20 mentions), autohemotherapy (11 mentions), and ozone therapy (11 mentions). Others mentioned in smaller quantities include microphysiotherapy, Ho'oponopono, sitz bath, compress, homeopathy, hemotherapy, micro-needling, cauterization, second intention healing, dressing, exfoliation, herbal therapy, photobiomodulation, vacuum or absorbent dressing, deworming, adhesive plaster, phototherapy, infiltrations, nitrogen, Dead Sea peeling, scraping, and reiki.

Perceptions of the Treatments

The motivation to use non-drug treatments and alternative procedures or therapies, as observed in the analysis, arises from both cost and accessibility factors, as well as from the abundance of comments endorsing these practices. There is even a pattern of replication where users, upon achieving positive results with their chosen practice, propagate it uniformly across multiple narratives, disregarding the nuances of individual experiences. This lack of awareness about the range of diagnoses that can cause similar symptoms is evident. Some reports mention discontinuing drug treatments in favor of these alternative solutions, as they are perceived to have fewer side effects compared to long-term drug use.

Out of the analyzed reports, 795 include feedback on the treatment received, irrespective of its nature. The majority of these (506 reports, 76.6%) indicate improvement in symptoms and/or quality of life for the patients. On the other hand, there are reports where the treatment showed no change in the patient's condition (237 reports, 29.8%), and some reports indicate that the treatment worsened their condition (46 reports, 5.8%). Additionally, six reports (0.8%) mention experiencing side effects from the treatments mentioned. Among the reports, 64 mention the cost of treatment.

Some discuss specific monetary values, while others inquire about the cost of certain medications or express concerns about the high cost and limited accessibility of appropriate medication. Alternative treatments often emerge as an affordable option for alleviating symptoms in this context.

DISCUSSION

Insight into the lived experiences of individuals with HS is critical for improving both medical care and quality of life outcomes. Understanding the thoughts, opinions, and preferences expressed by patients affected by this debilitating skin disorder requires delving beyond traditional survey responses and striving for deeper comprehension via spontaneous self-reported insights on social media platforms [19, 27]. Capturing naturally occurring online interactions and observations enables a virtual window into their decision-making, coping strategies, adaptive approaches, and desires for support networks.

HS symptomatology, as shown in our analysis, is multifaceted, reinforcing the complexity and heterogeneity of the disease [28]. The frequent occurrence of abscesses and nodules resonates with classical clinical descriptions of HS [29]. Pain, highlighted in the reports as a dominant symptom, remains a consistent finding in the literature, underscoring the debilitating nature of HS [30]. The manifestation of odor was also prevalent, further corroborating the findings of Jemec and Kimball [31], who reported it as a distinct characteristic of HS that significantly impairs patients' life. The large number of reports discussing the cyclic nature of HS—with periods of flares and remissions—is noteworthy. This feature has been previously identified in the literature and is thought to be a contributing factor to the psychological distress experienced by patients as a result of the unpredictable nature of flare-ups [32].

The significant impact of HS on patients' quality of life, as reflected in our analysis, aligns with previous research underscoring the considerable burden of this condition [28, 33]. The profound psychosocial implications identified

in the reports—feelings of embarrassment, social withdrawal, and low self-esteem—parallel the findings of Esmann and Jemec [32], highlighting the link between HS and psychological distress. Depression and anxiety, recurrent themes in our analysis, have been extensively documented in patients with HS, often associated with the chronic and unpredictable nature of the disease, as well as its visible manifestations [34]. The coexistence of HS with comorbidities emphasizes the need for multidisciplinary approaches, integrating both dermatological and psychological support [35, 36]. Patients' uncertainties about HS, including diagnosis and treatment, accentuate its complexity, aligning with Zouboulis and colleagues' call [37] for personalized treatment plans and Dufour et al.'s acknowledgment [38] of the wide symptom range that can complicate diagnosis. While dermatologists were primarily sought for their expertise in HS management, patients' encounters with diverse specialists suggest a multidimensional impact, advocating a more integrated care approach [39, 40]. Reports of misdiagnoses, struggles to find a specialist, and emergency room visits highlight an urgent need to improve HS awareness and healthcare system responsiveness.

The influence of HS on daily activities and lifestyle, such as clothing choices, work, and sleep, emphasizes the comprehensive disruptions caused by this condition. These accounts highlight the necessity for a holistic treatment approach that considers physical and psychosocial implications, to improve the overall quality of life [41]. Our insights reveal a complex journey for patients with HS, from symptom onset to diagnosis and treatment, which often involves delays [42, 43]. The treatment landscape for HS, as depicted in this study, is multifaceted, involving diverse pharmacological, non-pharmacological interventions, and procedural approaches [44]. This corresponds with a wealth of existing literature suggesting that HS management must be individualized and encompass both medical and surgical treatments [45]. Interestingly, the heavy reliance on over-the-counter medicines noted in this study indicates that patients may be attempting to self-manage their symptoms,

likely because of the lack of standardized treatments or poor access to healthcare. This is in line with studies demonstrating that HS is often undertreated, despite the significant burden it imposes [44, 46].

Within the realm of non-pharmacological oral interventions, herbal medicines are reported frequently. This usage could be attributed to perceptions of fewer side effects or as alternatives when conventional treatments are deemed ineffective or inaccessible [44]. This behavior is not exclusive to HS and has been seen in other chronic illnesses in general [47]. Topically, patients seem to employ a range of substances, many of which are not conventionally recommended for HS. This mirrors the general trend seen in dermatology where patients often resort to complementary and alternative therapies [48]. The most mentioned topical treatment is a combination of antiseptics and mild astringents, which may provide temporary relief for some HS symptoms but are not considered as a standard treatment. In procedural approaches, surgery emerges as a prevalent option, resonating with the existing literature that recognizes surgery as a cornerstone in HS management [49, 50]. The frequent mentions of alternative therapies, like autohemotherapy and ozone therapy, might represent patients' desperation in seeking symptom relief when standard treatments fall short. It is imperative for clinicians to proactively inquire about the utilization of such therapies, given that patients may exhibit reluctance to disclose this information because of apprehensions of subsequent interrogation or censure [51].

The study also reveals the behavioral patterns and perceptions of patients towards treatments, exposing a critical gap in understanding the nuances of HS treatment choices. The overall feedback on treatment received, showing an improvement in symptoms and/or quality of life in a majority of patients (76.6%), is encouraging. However, the reports reflect a notable motivation towards non-drug treatments and alternative therapies, driven by cost and accessibility factors as well as personal preferences and perceived fewer side effects compared to long-term drug use. Patients seem to favor treatments that improve their quality of

life, regardless of their conventional or alternative nature. Notably, patients' perception of the efficacy of their treatments does not always align with clinical evidence [52], suggesting a need for better communication between patients and providers regarding expectations and outcomes.

LIMITATIONS

The findings of this study, while valuable, should be viewed considering several limitations. The qualitative nature of the data focuses on individual experiences and thus may not be fully generalizable to the broader population of patients with HS. Additionally, the selection bias inherent in social media research may skew our sample towards patients who are more severely affected or actively seeking support. The self-reporting nature of the data collected could also introduce recall bias and subjective interpretation of experiences and symptoms. Moreover, the demographic of social media users often skews younger and more technologically savvy, potentially leading to an underrepresentation of older patients with HS or those less inclined to use social media. The focus on Brazilian Portuguese-speaking patients may also limit the generalizability of findings as a result of cultural, healthcare, and language differences.

CONCLUSION

This in-depth examination of narratives from individuals with HS underscores the complex, multidimensional reality of this disease and its impacts on patients' lives. The patient-reported symptoms highlight the heterogeneity of HS and reinforce the necessity for personalized, symptom-based approaches to care. A salient finding from our study is the significant prevalence of self-diagnosis and misdiagnosis, indicating a pressing need for improved awareness and understanding of HS among healthcare professionals. Misinformation and uncertainty, common among patients, further underline the demand for clear, accurate communication

between doctors and patients, and within the medical community at large.

The exploration of patients' treatment approaches sheds light on the frequent adoption of non-pharmaceutical interventions and alternative treatments. Such findings reflect not only a potential inadequacy of current medical options and accessibility issues but also patients' search for more natural, side-effect-free alternatives. This trend warrants further investigation, to assess the effectiveness of these non-traditional treatment modalities and their potential incorporation into comprehensive HS care. Quality of life impacts stand out in our analysis, with individuals with HS wrestling with chronic pain, discomfort, and psychological distress. The visibility of HS symptoms often intensifies feelings of stigma and damages self-esteem, underscoring the importance of holistic, psychosocial support as a component of medical care.

This study unveils the intricacies of HS and the myriad ways it permeates individuals' lives. Conclusively, these findings underscore the importance of an integrated, patient-centered approach to HS care. This approach should encompass a range of strategies, from timely and accurate diagnosis, through comprehensive treatment plans, to supportive care aimed at enhancing patients' quality of life. Our study illuminates the way forward, stressing the urgency of addressing the complexities of HS in a comprehensive manner that truly resonates with patient experiences. Such real-world, patient-reported data can complement traditional research methods, providing a more holistic and nuanced understanding of a complex condition like HS. This can be instrumental in designing more personalized, patient-centered care models and informing future research directions.

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Data Availability. The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

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Ethical Approval. All the data collected, analyzed, and presented in this study were exclusively sourced from public and openly accessible platforms. All the narratives collected were anonymized prior to any analysis. This article underwent review by the scientific committee of Novartis (code CLR-12165/AIN-MS-117664) and was approved for publication without requiring any additional review by an ethics committee.

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