Patient Preference and Adherence

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ORIGINAL RESEARCH

Exploring the Needs and Preferences of Patients with Port-Wine Stain and Associated Syndromes: A Qualitative Analysis of Social Media Discussions

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Purpose: Patients with port-wine stain (PWS) and related syndromes often face multifaceted challenges in disease management, including prolonged treatment cycles, appearance-related distress, and psychological burdens. Social media has become an important platform for these individuals to obtain information and share experiences. However, there is a lack of systematic qualitative research exploring their genuine needs. This study analyzes content from social media to identify patients' core concerns during the diagnostic and therapeutic process, providing both theoretical foundations and practical references for developing patient-centered care models.

Methods: This study systematically analyzed PWS-related posts published between 2010 and 2023 across open social media platforms including Twitter, Facebook, and Baidu. A stratified sampling method was applied, and natural language processing was used to extract keywords and thematic sentences. Through expert review and AI-assisted classification, core patient needs in disease management were qualitatively summarized and categorized.

Results: A total of 1528 social media posts were analyzed, yielding 4,190 extracted keywords categorized into six major themes. Treatment-related concerns were the most prominent (30.04%), particularly focusing on treatment choices, side effects, and delayed efficacy. Diagnostic confusion was also frequently mentioned (24.41%). A significant number of posts conveyed emotional distress and a strong desire for shared experiences, with emotional support themes accounting for 4.19%, highlighting their importance. Some patients proactively shared treatment journeys, contributing to a supportive and empathetic community atmosphere.

Conclusion: This study distilled key needs from authentic patient expressions and found that beyond clinical diagnosis and treatment, PWS patients also highly value emotional support and anxiety relief regarding relapse. These findings underscore the necessity of building patient-centered care systems that integrate emotional and psychological support while managing treatment expectations. Future studies should combine quantitative research and clinical data to refine variable analyses and develop educational and intervention strategies tailored to real online patient needs.

Keywords: port-wine stain, social media analysis, patient-centered care, qualitative research

Introduction

Port-wine stain (PWS) is a benign congenital capillary malformation that affects approximately 0.3% to 0.5% of newborns worldwide.[1] PWS commonly appears in the head and neck region. When associated with extensive skin lesions, thickening of the skin and soft tissues, or nodules, it can significantly impact the patient's appearance, leading to psychological stress and social adaptation difficulties.[2] Moreover, some PWS cases are associated with genetic

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syndromes such as Sturge-Weber syndrome (SWS) or Klippel-Trenaunay syndrome (KTS), which may lead to neurological abnormalities and limb malformations, further affecting quality of life and social participation.[3–7]

In addition to medical treatment, psychological and social support is essential for individuals with PWS and related syndromes.[8] With the rapid expansion of online healthcare resources, an increasing number of patients now use social media and health communities to discuss their conditions, share treatment experiences, and seek peer support.[9] Compared to traditional surveys or interviews, social media platforms provide more spontaneous and authentic patient expressions, reflecting real-life concerns from a patient-centered perspective.[10] These platforms often contain multidimensional information—ranging from daily life and treatment experiences to emotional responses—offering rich data to uncover genuine patient needs.[11]

While social media-based qualitative analyses have been successfully applied to chronic diseases such as psoriasis, cancer, and diabetes,[12] studies focusing on PWS patients remain largely reliant on traditional quantitative surveys and clinical interviews. Few have systematically explored PWS-related patient discussions on social media. This study aims to analyze real-world expressions from PWS patients and their families on various platforms, with a focus on their educational and psychosocial needs. By complementing conventional research approaches, this method offers valuable insights for developing effective patient education and intervention strategies tailored to actual user experiences.[13]

Methods

This study analyzed user-generated content related to port-wine stain (PWS) across three major open-access social media platforms—Twitter, Facebook, and Baidu—from 2010 to 2023. The target population included patients and their families from Asia (China, South Korea, Nepal, India), North America (United States), and Europe (United Kingdom). Search terms included "Port-Wine Birthmark (PWB)" and "Port-Wine Stain (PWS)", applied to platforms that allowed public access and had been updated within one month of data extraction. Only active, open forums were included. Stratified random sampling was used, based on the year of the post, with a sampling ratio of 10:1. Extracted data included complete post titles and content (excluding comments). The access date for data collection was December 2023.

A total of 1,528 posts were retrieved and analyzed (Figure 1). Posts were reviewed independently by three dermatologists, with non-relevant or non-textual posts excluded. Representative keywords and thematic sentences were extracted from each post. These were categorized into six major thematic domains using a combination of expert consensus and AI-assisted classification via ChatGPT-4o. The six themes were: diagnosis, treatment, symptoms, emotional support, advice, and others. Each major theme was further divided into five subthemes. The frequency of each category was quantified (see Table 1).

To ensure the reliability of thematic classification, two board-certified dermatologists independently reviewed all AI-classified posts. Their acceptance rates were 84.93% and 89.73%, respectively, with an overall observed agreement of 91.98% (Cohen's $\kappa = 0.64$). Discrepancies were resolved by consensus to finalize the dataset, and representative quotes were retained in the original patient language—often expressed in first-person—for authenticity (see Table 2). Thematic classification was refined through iterative discussion to ensure clarity and minimize overlap.

Natural language processing tools were used to analyze the data: Jieba for Chinese word segmentation and NLTK for English. Word frequencies were calculated post-tokenization to generate the final thematic distribution (Figure 2). All data were sourced from publicly accessible platforms. No identifiable personal data or clinical trials were involved. Before analysis, all content was anonymized. Ethical approval was granted by the Biomedical Ethics Review Committee of West China Hospital, Sichuan University.

Results

A total of 1,528 social media posts related to Port-Wine Stain (PWS) were collected and analyzed, comprising 1,298 English-language entries and 230 from Chinese-language platforms. From these, 146 distinct keywords were identified, occurring a total of 4,190 times. Through thematic classification, six major domains of patient concerns emerged: treatment, diagnosis, symptoms, emotional support, advice, and other general topics (see Table 1 and Figure 3). The thematic distribution table (see Table 2) and the word cloud (Figure 2) generated from keyword frequencies illustrate the main patient concerns and highlight the most frequently discussed topics in the dataset.

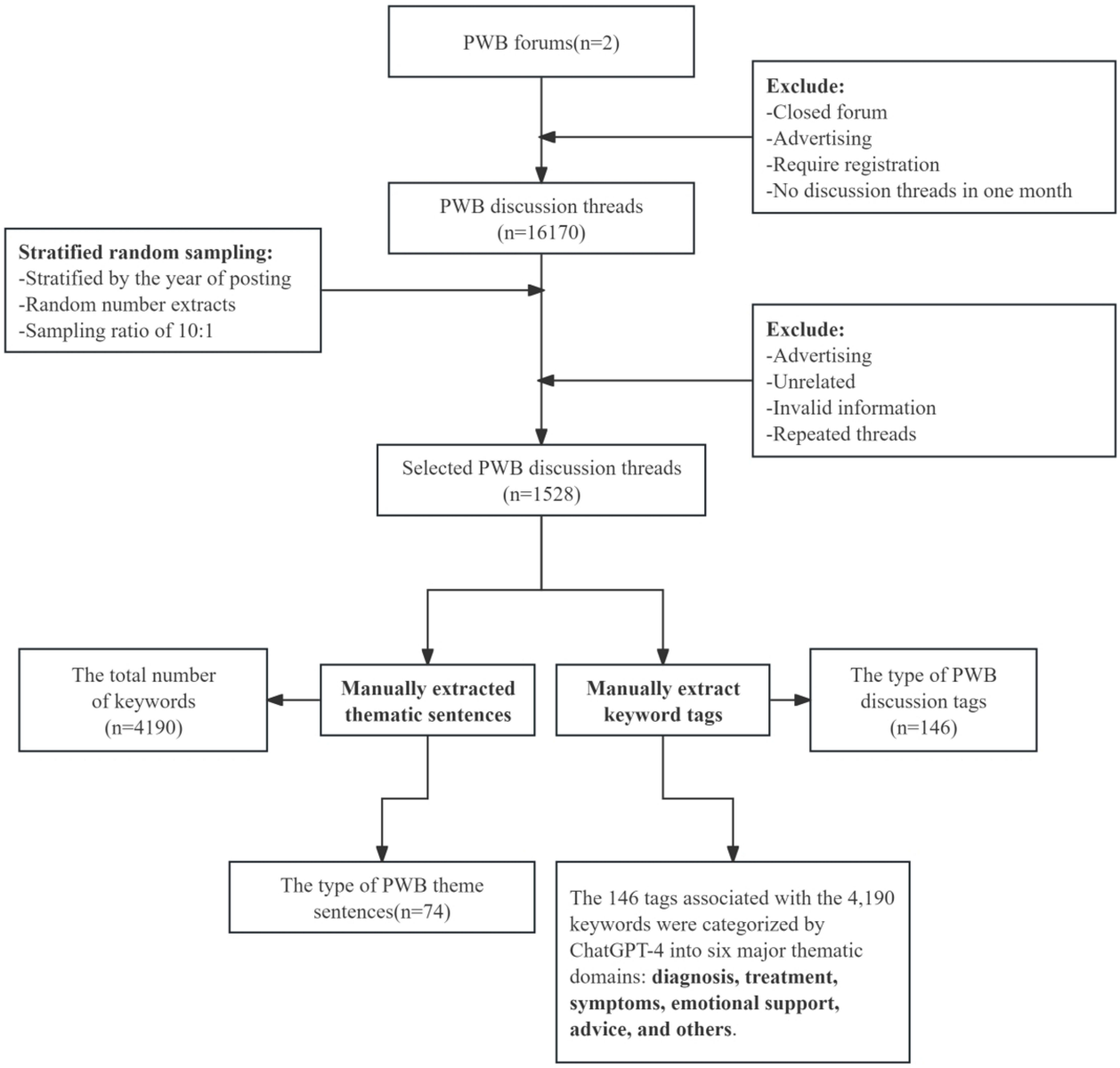

Figure 1 Workflow of the Qualitative Study on Common Needs of PWS Patients Based on Social Media Data.
Notes: This flowchart illustrates the methodological steps used in the qualitative analysis of social media content related to Port-Wine Stain (PWS). Posts were retrieved from Twitter, Facebook, and Baidu, followed by stratified random sampling, manual review by dermatologists, thematic extraction, and AI-assisted categorization. Exclude marks the exclusion criteria separately applied to forum posts and Q&A entries. Manually extracted thematic sentences and keywords were identified, with keywords categorized into six types: diagnosis, treatment, symptoms, emotional support, advice, and others.
Abbreviations: PWS, Port-Wine Stain; PWB, Port-Wine Birthmark.

Among these domains, treatment-related concerns were the most frequently discussed, accounting for 30.04% of all posts. Patients and caregivers commonly shared doubts and anxieties about the choice of treatment methods, anticipated outcomes, and adverse effects. Notably, 18.76% of keywords centered on treatment options, highlighting the uncertainty patients face in selecting among laser therapy, photodynamic therapy, and other modalities. Many parents of infants with facial PWS expressed particular concern about procedural pain and anesthesia risks, with some questioning the potential neurological or cardiac effects of photodynamic agents. In one post, a parent asked, "Has anyone used Hemoporfin photodynamic therapy on their child? Does it affect brain development or the heart?" This prompted a series of responses

Table 1 Thematic Domains and Subthemes of Patient Concerns Related to Port-Wine Stain (PWS)

Major Thematic Domains (Number of Threads, %)	Sub-Themes	(Number of Keywords, %)
Treatment (459, 30.04%)	PWS treatment options	(786, 18.76%)
	PWS anesthesia use	(193, 4.61%)
	PWS treatment side effects	(103, 2.46%)
	Laser treatment for PWS	(93, 2.22%)
	PWS pain management	(84, 1.99%)
Diagnosis (373, 24.41%)	Newborn PWS identification	(540, 12.89%)
	Port-Wine Stain (PWS) diagnosis	(271, 6.47%)
	PWS specialist	(134, 3.21%)
	Port-Wine Birthmark (PWB) symptoms	(60, 1.43%)
	Genetic testing for Sturge-Weber syndrome	(17, 0.41%)
Emotional support (64, 4.19%)	PWS emotional support	(59, 1.41%)
	PWS psychological impact	(58, 1.37%)
	PWS coping strategies	(28, 0.67%)
	PWS patient community	(28, 0.67%)
	PWS family support	(3, 0.07%)
Advice (62, 4.08%)	PWS patient experiences	(74, 1.77%)
	PWS management tips	(33,0.79%)
	Best practices for PWS	(29, 0.68%)
	PWS care recommendations	(23, 0.55%)
	PWS treatment advice	(12, 0.29%)
Symptoms (58, 3.79%)	PWS skin thickening	(40, 0.95%)
	PWS complications	(39, 0.93%)
	Sturge-Weber syndrome symptoms	(34, 0.81%)
	PWS glaucoma	(24, 0.57%)
	PWS seizures	(22, 0.53%)
Others (512, 33.51%)	Port-Wine Stain information	(920, 21.96%)
	Others	(220, 5.25%)
	PWS forums and discussions	(76, 1.82%)
	PWS parental guidance	(95, 2.27%)
	PWS patient stories	(93, 2.21%)

Notes: This table presents the results of a qualitative analysis of 1,528 social media posts concerning PWS. Six major thematic domains were identified, each containing five subthemes. The number and percentage of posts and associated keywords are provided to indicate the relative prominence of each concern.
Abbreviations: PWS, Port-Wine Stain; PWB, Port-Wine Birthmark.

Table 2 Frequently Expressed Patient Needs Based on Thematic Sentences from Social Media

Questions	Frequency (N, %)
After treatment, the condition still relapses. I am really exhausted, but I am still holding on.	(1086, 61.56%)
Identification of disease types and basic inquiries.	(225, 12.76%)
The helplessness after relapse or changes in skin lesions.	(111, 6.29%)
After treatment, my face is severely swollen, and I do not know if it will leave scars.	(32, 1.81%)
I wish the doctor could give more advice and not leave me to guess.	(16, 0.91%)
Concerns from parents about the progression of their baby's condition.	(16, 0.91%)
Confusion about choosing between different hospitals, equipment, or treatment options.	(14, 0.79%)

(*Continued*)

Table 2 (Continued).

Questions	Frequency (N, %)
I am very anxious about anesthesia.	(11, 0.62%)
I feel a lot of psychological pressure from the treatment.	(10, 0.57%)
I worry about delaying the treatment.	(9, 0.51%)
I am concerned that my condition may become uncontrollable.	(8, 0.45%)
I am worried about physical harm from the treatment.	(8, 0.45%)
I am confused about choosing the treatment method.	(7, 0.40%)
I worry about how the treatment will affect my child's life.	(7, 0.40%)
I am afraid of the treatment process.	(7, 0.40%)
I hope to receive emotional support.	(7, 0.40%)
I am worried about the heavy financial burden.	(6, 0.34%)
I hope my family can understand my choices.	(6, 0.34%)
I am concerned about the reactions after treatment.	(6, 0.34%)
I am worried about my child's future schooling or social life.	(6, 0.34%)
I am confused by the changes in my birthmark.	(6, 0.34%)
I am trying to accept it, but I still feel conflicted inside.	(5, 0.28%)
I do not know what to do next after starting treatment.	(5, 0.28%)
I am about to give up, but I just cannot bring myself to.	(5, 0.28%)
I am uncertain if this is PWS.	(5, 0.28%)
I am worried about the side effects of the treatment.	(5, 0.28%)
I am concerned whether this will be passed on to my child.	(5, 0.28%)
I see others have be en treated successfully, but I want to try too, though I am scared.	(5, 0.28%)
I am afraid my family will oppose the treatment, and I do not know what to do.	(5, 0.28%)
I hope to have the option for remote consultations.	(5, 0.28%)

Notes: This table summarizes representative patient concerns that occurred five or more times in the dataset, extracted from a total of 1,764 thematic sentences. Expressions reflect emotional burden, uncertainty in diagnosis, treatment decision-making, and social support needs. Frequency is provided in absolute count and percentage.
Abbreviation: PWS, Port-Wine Stain.

from other users, providing detailed descriptions of postoperative symptoms, recovery experiences, and pre-treatment assessments such as echocardiograms and neurological consultations.

Diagnosis-related themes constituted the second most prominent domain, comprising 24.41% of the dataset. A significant portion of these posts related to early-stage identification of PWS, especially among newborns. In many instances, caregivers uploaded images seeking community feedback, often accompanying the post with statements like: "My baby has a red mark on the back of her head that hasn't faded since birth. Could this be a port-wine stain?" Confusion regarding terminology and diagnostic criteria was common, and concerns about possible syndromic associations—particularly with Sturge-Weber Syndrome—were raised. Posts discussing genetic testing, though fewer in number

Figure 2 Word Cloud of High-Frequency Keywords from PWS-Related Social Media Posts.
Notes: The word cloud visualizes the frequency of keywords extracted from 1,528 PWS-related posts. Larger words indicate higher frequency, reflecting the dominant concerns of patients and families. Common terms include "treatment", "diagnosis", "pain", and "relapse", underscoring key areas of patient focus.
Abbreviation: PWS, Port-Wine Stain.

(0.41%), revealed ambivalence about test utility and interpretation. Some users reported positive chromosomal findings without clinical manifestations, while others cited clinician reluctance to recommend testing at early stages.

Emotional and psychological needs, though less quantitatively dominant, emerged as a substantial qualitative theme. Emotional support-related posts comprised 4.19% of the total, but a notable portion of thematic sentences (61.56%) reflected deep psychological exhaustion and persistence in the face of relapse. Expressions such as "I'm really exhausted, but I'm still holding on" and "I feel helpless every time the lesions change again" were recurrent, indicating a pervasive sense of chronic emotional burden. Shame, guilt, and fear of public scrutiny were also evident. One mother wrote about avoiding public outings with her child due to the "curious and sometimes judgmental" looks from strangers. Others attempted to support one another by sharing coping mechanisms, such as using makeup for camouflage or joining peer support groups.

Although accounting for a smaller percentage (3.79%), symptom-related content addressed clinical manifestations such as skin thickening, nodular overgrowth, seizures, and glaucoma. These posts often lacked technical detail but provided valuable insight into patient-reported experiences, which may be underrepresented in clinical documentation. Advice-related content (4.08%) largely involved experience sharing and self-management strategies. Many patients

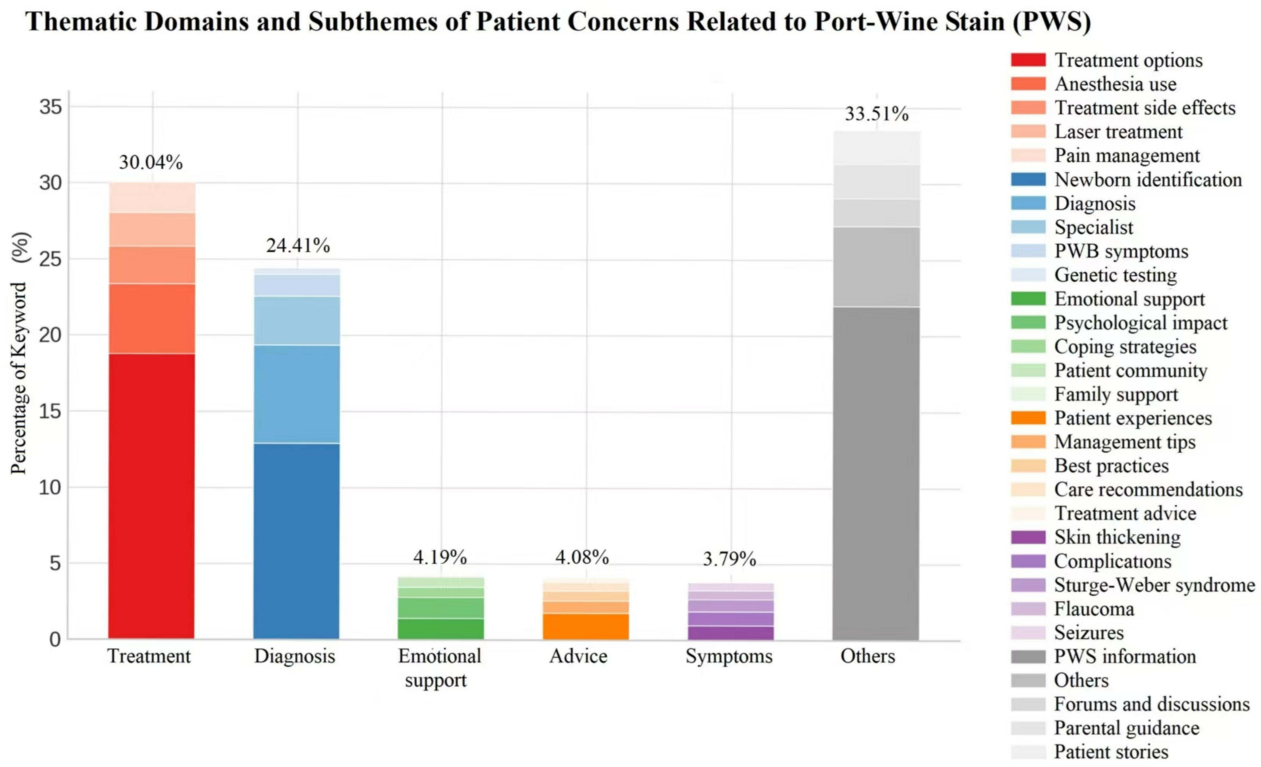

Figure 3 Thematic Domains and Subthemes of Patient Concerns Related to Port-Wine Stain (PWS).
Notes: This figure illustrates the distribution of thematic domains and their corresponding subthemes derived from 1,528 patient and caregiver posts across major social media platforms. The six major domains—treatment, diagnosis, symptoms, emotional support, advice, and others—are visualized as bar groups. Each bar within a group represents the frequency percentage of a specific subtheme (eg, "treatment options", "anesthesia", "psychological impact"), reflecting the diversity and intensity of patient concerns in each domain. Cumulative percentages for each major domain are annotated above the grouped bars. This figure complements Table 1 by providing an intuitive overview of the relative prominence and internal structure of expressed needs.
Abbreviations: PWS, Port-Wine Stain; PWB, Port-Wine Birthmark.

documented their treatment journeys, offered encouragement to peers, or requested suggestions on selecting healthcare providers, treatment centers, or home care techniques.

The final domain, categorized as "other", made up 33.51% of all content. Posts in this domain typically conveyed general information-seeking behavior, family inquiries, or personal narratives. Several adult patients shared long-term perspectives on living with PWS, describing experiences across childhood, adolescence, and adulthood. In these posts, users not only recounted therapeutic milestones but also explored themes of acceptance, self-image, and resilience. Some posts were accompanied by photos, treatment timelines, or records of physician interactions, reflecting a semi-structured pattern of community-based narrative exchange.

Together, these findings underscore the complexity and multidimensionality of the lived experience with PWS. While treatment remains the dominant concern, emotional resilience, diagnostic clarity, and patient empowerment are equally salient themes that warrant attention in future clinical and psychosocial interventions.

Discussion

This study provides a comprehensive qualitative analysis of the lived experiences of patients with port-wine stain (PWS) and associated syndromes by examining real-world expressions on social media platforms. The findings highlight that treatment-related uncertainty, emotional exhaustion, and the need for personalized information are central themes in patient discourse, underscoring the critical role of patient-centered care models.

Among the most striking insights is the pervasive sense of therapeutic fatigue and emotional distress among patients, particularly in the context of recurrent lesions. Many patients described a cycle of hope followed by disappointment, with

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delayed or suboptimal treatment outcomes intensifying feelings of helplessness. These experiences reflect core elements of the Health Belief Model,[14] where discrepancies between treatment expectations and perceived efficacy affect both adherence and psychological well-being.[15] To address this, future clinical pathways must incorporate mechanisms for setting realistic expectations and offering psychological support throughout the therapeutic journey.[16,17]

Another prominent theme was diagnostic confusion, especially during infancy. Parents frequently expressed anxiety over the recognition, classification, and progression of birthmarks. This diagnostic ambiguity, often exacerbated by the absence of accessible specialist care or genetic counseling, reinforces the importance of timely information delivery and professional guidance. Enhancing access to expert-led digital health content or integrating virtual triage systems could help bridge this gap.[18]

The emotional landscape revealed in these posts challenges the often treatment-focused orientation of dermatologic care. Although only a minority of posts explicitly addressed emotional support, the depth and intensity of emotional expression suggest that psychosocial distress is both common and underreported. Phrases such as "I feel ashamed" or "I no longer have the courage to face others" indicate profound internalized stigma. These insights align with previous findings that emotional concerns are frequently overlooked in routine dermatological consultations.[19] Incorporating structured psychosocial screening and referral processes into standard care could help address this unmet need.[20]

The use of social media as a data source in this study proved advantageous in capturing candid, unfiltered patient voices. However, the unregulated nature of these platforms also enables the spread of misinformation, which may further contribute to anxiety and inappropriate treatment decisions.[21] Therefore, healthcare institutions should consider establishing verified online communication channels to deliver accurate, empathetic, and evidence-based content. Such efforts could improve digital health literacy and reduce patients' reliance on potentially unreliable sources.[22]

Limitations

Several limitations must be acknowledged. First, the study is constrained by its reliance on user-generated content from publicly accessible platforms, which may not fully represent the diversity of the PWS patient population. Individuals with limited internet access, cognitive impairment, or low literacy levels are likely underrepresented, thereby introducing potential sampling bias. Second, due to the anonymity inherent to social media, the authenticity of some posts cannot be independently verified. Although we applied rigorous manual screening to exclude non-patient content, the lack of clinical validation poses challenges for interpreting self-reported experiences. Third, the nature of social media discourse is inherently unstructured, emotionally charged, and repetitive. While multiple coding and AI-assisted classification rounds were employed to refine thematic categories, some emotional nuances or borderline cases may have been oversimplified or misclassified. Fourth, the posts lacked accompanying clinical data, such as lesion size, anatomical location, treatment history, or comorbidities, limiting our ability to correlate expressions with clinical context. Finally, while inter-rater reliability was enhanced through dual coding and consensus discussion, subjective interpretation inevitably influenced thematic assignments, particularly in emotionally complex narratives.

Conclusion

By analyzing patient-generated content on social media platforms, this study identifies not only commonly recognized concerns such as treatment efficacy and diagnostic accuracy, but also underappreciated domains such as emotional support, stigma, and psychological resilience. These findings advocate for the development of comprehensive care models that extend beyond clinical treatment to include patient education, expectation management, and mental health support.

Future research should incorporate quantitative approaches, real-world clinical data, and diverse demographic representation to validate these qualitative insights. Integrating patient voices from digital platforms into the design of intervention programs may enhance relevance, responsiveness, and impact. Ultimately, sustained attention to the psychosocial dimensions of PWS management will be essential for improving long-term patient outcomes and satisfaction.

Ethics Statement

This study has been reviewed and approved by the Biomedical Ethics Committee of West China Hospital, Sichuan University (Approval No. 2024.317).The research is based on user-generated posts from open social media platforms, Baidu Tieba and Sina Weibo, which are publicly accessible. The data collection and usage strictly adhered to the terms of service and platform usage agreements of both Baidu Tieba and Sina Weibo, without violating any data usage clauses. As this study only involves analysis of publicly posted content and does not involve the collection or disclosure of users' private information, no additional permissions were required. The research process and the published content do not contain any personally identifiable information. All data have been anonymized to protect user privacy.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors report no conflicts of interest in this work.

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