

Patient-Perceived Barriers and Facilitators to Healthcare Access in Hidradenitis Suppurativa: A Scoping Review

Authors

Dijle Akdag¹ Dr Laura Howells¹ Dr Lydia Tutt¹ Dr Hannah Wainman²

1. Centre of Evidence Based Dermatology (CEBD), School of Medicine, University of Nottingham, UK
2. Centre for Applied Excellence in Skin and Allergy Research (CAESAR), Centre for Academic Primary Care, Bristol Medical School, University of Bristol, UK

Abstract

Objective: This scoping review aims to systematically map and characterise existing evidence on patient-perceived barriers and facilitators influencing help-seeking for Hidradenitis Suppurativa (HS) within healthcare settings.

Introduction: HS is a chronic autoinflammatory skin condition affecting intertriginous, apocrine gland-bearing areas, associated with considerable physical and psychosocial burden, including depressive symptoms in one-third of patients and substantial morbidity. Despite this, HS remains underdiagnosed, with a mean diagnostic delay of 7-10 years. Evidence on patient-perceived barriers to help-seeking and healthcare access is limited, highlighting the need to map and characterise these barriers to inform interventions for timely diagnosis and management.

Inclusion Criteria: Studies including individuals with HS, regardless of age, sex, or ethnicity, and caregivers or healthcare professionals reporting patient-perceived barriers, will be eligible. Patient-reported barriers occurring at any stage of the healthcare continuum, across diverse healthcare systems, settings, and countries, will be considered. Studies not reporting patient-perceived barriers, focusing exclusively on non-patient perspectives, or outside formal healthcare will be excluded.

Methods: A comprehensive search strategy will be developed in collaboration with an information specialist. Key databases: MEDLINE; CINAHL; PsycINFO; and Embase will be systematically searched in November 2025, limited to English and Turkish-language studies. Grey literature and handsearching will be included. Following Joanna Briggs Institute (JBI) methodology, two reviewers will independently screen titles, abstracts, and full texts against predefined eligibility criteria, with a third reviewer resolving discrepancies. Data will be extracted using the standardised JBI extraction tool to map and characterise the evidence.

Keywords: diagnostic delay; disengagement; help-seeking; psychosocial factors; self-management.

Introduction

Hidradenitis Suppurativa (HS), also known as Acne Inversa or Verneuil's disease, is a chronic, recurrent, and debilitating autoinflammatory disorder of the hair follicle¹. It is characterised by the development of painful, deep-seated nodules, abscesses, and draining sinus tracts² in intertriginous, apocrine gland-bearing regions such as the axillae, groin, perianal, perineal, and inframammary areas³. HS affects an estimated 0.05-4.1%^{4,5} of the population and demonstrates a marked female predilection, occurring approximately three times more frequently in women than in men^{6,7}. The condition disproportionately affects individuals of African American descent⁸, potentially reflecting underlying genetic susceptibility, and typically presents in early adulthood⁹. Diagnosis remains challenging, with a mean diagnostic delay of 7-10 years¹⁰, exacerbating physical morbidity and psychological distress. While diagnostic delay has been explored from the perspective of healthcare professionals, limited evidence exists regarding patient-perceived barriers to help-seeking and healthcare engagement.

Understanding these barriers is critical to improving early detection and management. A recent European survey found that patients, on average, delay seeking medical help for approximately two years after symptom onset¹¹, citing reasons such as perceiving the condition as not serious, embarrassment or shame, self-managing symptoms, and difficulties accessing timely appointment¹². HS imposes a substantial physical and psychosocial burden; recurrent lesions and chronic pain often lead to scarring, restricted mobility, and reduced quality of life¹³. Visible lesions and malodour may contribute to social stigma, isolation, and diminished self-esteem¹⁴, while psychiatric comorbidities such as depression and anxiety are highly prevalent, with 42.9% of individuals with HS carrying a diagnosis of depression¹⁵. The chronic, relapsing nature of HS, compounded by its profound psychosocial impact, underscores the urgent need to identify and address patient-perceived barriers to help-seeking to facilitate timely diagnosis and comprehensive, patient-centred care.

Review question

Primary question:

What patient-perceived barriers and facilitators influence individuals with Hidradenitis Suppurativa in seeking or accessing care in healthcare settings?

Secondary questions:

1. How are psychosocial factors, including stigma, embarrassment, or psychological distress reported as influencing help seeking behaviour?
2. What strategies do patients use to manage HS prior to seeking professional care? And how might these relate to barriers encountered?
3. How do patient-perceived barriers vary by demographic or contextual factors, such as age, gender, socioeconomic status, or cultural background?
4. To what extent does patients' knowledge of HS and its treatment options influence decisions to seek care?
5. Which patient groups or barrier types are underrepresented in existing literature?

Note: As this is a scoping review protocol, the sub-questions are intended to guide data extraction and mapping of the evidence; It is not expected that all sub-questions will be fully answered.

Inclusion criteria

Participants

Studies including individuals of any age, sex, ethnicity, or disease severity with Hidradenitis Suppurativa (HS) will be eligible. Studies of caregivers or healthcare professionals will be considered only if reporting patient-perceived barriers. Individuals with HS will be included regardless of additional dermatological conditions or comorbidities; studies that include multiple skin conditions will also be eligible if data specific to HS can be meaningfully extracted. Studies focusing solely on healthcare providers' perspectives or on individuals without HS will be excluded.

Concept

The concept of interest is patient-perceived barriers to seeking or accessing healthcare for HS, including psychological, social, structural, and knowledge-related factors, across all stages of the healthcare continuum: diagnosis, management, accessing psychological support, treatment adherence, and referrals. This includes experiences such as disengagement from care or self-management strategies. Only studies reporting barriers as perceived or experienced by patients will be included; studies that do not report patient-reported barriers to healthcare will be excluded. Facilitators, such as positive healthcare experiences or enabling factors, will also be extracted where reported.

Context

All healthcare settings will be eligible, including primary, secondary, and specialist dermatological care, across public, private, or mixed healthcare systems. Studies from any country, region, or cultural context will be considered. Those limited to non-healthcare settings or contexts unrelated to healthcare access will be excluded.

Types of sources

This scoping review will consider a wide range of study designs, including experimental, observational, and qualitative research, as well as systematic reviews and text or opinion papers. Eligible sources may include randomized and non-randomized controlled trials, cohort or case-control studies, cross-sectional designs, case reports, and qualitative studies using approaches such as phenomenology, grounded theory, or ethnography. All sources must address patient-reported barriers to healthcare for individuals with Hidradenitis Suppurativa.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews¹⁶. This protocol will be prospectively registered on the Centre of Evidence Based Dermatology's protocol registration page (<https://www.nottingham.ac.uk/research/groups/cebd/resources/protocol-registration.aspx>).

Search strategy

The search strategy will aim to locate both published and unpublished studies using a three-step search approach. Initially, a limited search of MEDLINE (via OVID), CINAHL (via EBSCOhost), PsycINFO (via OVID), and Embase (via Elsevier) was undertaken to identify relevant articles on the topic. The text words contained in the titles and abstracts of retrieved articles, along with index terms used to describe them, were used to develop a full search strategy for all included databases (see Appendix I), with guidance from an information specialist. The full MEDLINE search strategy is outlined in Table S1 and will be adapted as appropriate for each database and information source. The final search strategy will be peer-reviewed internally by the research team prior to implementation. Reference lists of included studies and relevant reviews, as well as grey literature sources, will also be manually searched to identify additional studies.

Studies published from inception to November 2025 will be eligible to ensure comprehensive coverage of the literature over time. The search will be limited to English and Turkish-language publications to reflect the language proficiency of the review team and to ensure accurate interpretation of study findings.

Study/Source of evidence selection

Following the search, all identified citations will be collated and uploaded into Rayyan (Rayyan Systems Inc., Doha, Qatar) for duplicate removal. Following a pilot test, titles and abstracts will be screened independently by two reviewers against the predefined inclusion criteria. The full texts of potentially eligible papers will then be assessed in detail by two independent reviewers. Reasons for exclusion at the full text stage will be recorded and reported in the final scoping review. Any disagreements will be resolved through discussion with a third reviewer. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA 2020 flow diagram¹⁷.

Data extraction

Data will be extracted from papers included in the scoping review by two or more independent reviewers using the standardised Joanna Briggs Institute (JBI) data extraction tool for scoping reviews¹⁶. Extracted information will include details on participants (e.g., age, sex, comorbidities), concept (patient-perceived barriers to healthcare access), context (healthcare setting, country, healthcare system type), study methods, and key findings relevant to the review questions (see Appendix II). Any modifications to the JBI tool, such as additional fields to capture underrepresented patient groups or specific barrier types, will be described in the full review.

While it is best standard to use 2 people, as it reduces bias and improves reliability, some subjective interpretation may remain, particularly for complex or nuanced barriers, given resource constraints this may be done for just a selection of the articles if needed to meet deadlines. Any limitations in the extraction process will be acknowledged in the final review.

Data analysis and presentation

Extracted data will be mapped out to systematically describe what is known about patient-perceived barriers and facilitators across the healthcare continuum. Results will be presented in tables and/or charts, with a narrative summary describing how the findings relate to the review objectives and research questions. This approach will allow patterns, gaps, and underrepresented patient groups to be clearly identified within the current evidence base.

Acknowledgements

The author would like to thank Kate Clement, Information Specialist at the University of Nottingham, for her guidance in developing the search strategy. This review contributes to the requirements for the Bachelor of Medicine, Bachelor of Surgery (BMBS) degree for Dijle Akdag, following completion of the BMedSci research.

Funding

This scoping review did not receive specific funding. No funders had any role in the design, conduct, or reporting of the review.

Declarations

Patient and public involvement from key individuals helped inform the focus of this scoping review.

Author contributions

Dijle Akdag conceptualised the research questions, developed the protocol, conducted primary data screening and extraction, and drafted the manuscript. Dr Laura Howells originated the initial idea for the review. Dr Laura Howells and Dr Lydia Tutt provided supervision, methodological guidance, and input on protocol development. Dr Hannah Wainman contributed clinical expertise relevant to the review topic. All authors critically reviewed the protocol and approved the final version.

Conflicts of interest

The authors declare that there are no conflicts of interest related to this project.

References

1. Zouboulis CC, Desai N, Emtestam L, Hunger RE, Ioannides D, Juhász I, et al. European S1 guideline for the treatment of hidradenitis suppurativa/acne inversa. *J Eur Acad Dermatol Venereol*. 2015;29(4):619-644. doi:10.1111/jdv.12966
2. Goldburg SR, Strober BE, Payette MJ. Hidradenitis suppurativa. *J Am Acad Dermatol*. 2020;82(5):1045-1058. doi:10.1016/j.jaad.2019.08.090
3. Ballard K, Sathe NC, Shuman VL. Hidradenitis suppurativa. In: *StatPearls* [Internet]. Treasure Island (FL): StatPearls Publishing; 2024 [updated 2024 May 6]. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK534867/>
4. Saunte DML, Jemec GBE. Hidradenitis suppurativa. *JAMA*. 2017;318(20):2019. doi:10.1001/jama.2017.16691
5. Marzano AV, Magnoni C, Micali G, Magnis AD, Pintori G, Fiorini S, et al. Improving hidradenitis suppurativa management: consensus statements from physicians and patients' perspectives. *Arch Dermatol Res*. 2024;316(8):ePub ahead of print. doi:10.1007/s00403-024-03316-2
6. Dufour DN, Emtestam L, Jemec GBE. Hidradenitis suppurativa: a common and burdensome, yet under-recognised, inflammatory skin disease. *Postgrad Med J*. 2014;90(1062):216-221. doi:10.1136/postgradmedj-2013-131994
7. Scala E, Cacciapuoti S, Garzorz-Stark N, Megna M, Marasca C, Seiringer P, et al. Hidradenitis suppurativa: where we are and where we are going. *Cells*. 2021;10(8):2094. doi:10.3390/cells10082094

8. Ulschmid C, Serrano L, Wu R, Roth GM, Sokumbi O. African American race is a risk factor for severe hidradenitis suppurativa. *Int J Dermatol*. 2023;62(5):657-663. doi:10.1111/ijd.16428
9. Sabat R, Alavi A, Wolk K, Wortsman X, McGrath B, Garg A, et al. Hidradenitis suppurativa. *Lancet*. 2025;405(10423):ePub ahead of print. doi:10.1016/S0140-6736(24)02475-9
10. Aparício Martins I, Figueira Vilela B, Cabete J. Diagnostic delay in hidradenitis suppurativa: still an unsolved problem. *Skin Appendage Disord*. 2023;10(2):129-132. doi:10.1159/000534845
11. Howells L, Lancaster N, McPhee M, Bundy C, Ingram JR, Leighton P, et al. Thematic synthesis of the experiences of people with hidradenitis suppurativa: a systematic review. *Br J Dermatol*. 2021;185(5):921-934. doi:10.1111/bjd.20523
12. Kokolakis G, Vilarrasa E, Garg A, Alarcon I, Go M, Newbold G, et al. Patient perspectives on the impact of living with hidradenitis suppurativa: results from the global 'HS Uncovered' burden of disease survey. *JEADV Clin Pract*. 2025;4(4):920-929. doi:10.1002/jvc2.70071
13. Jemec GBE. Quality of life considerations and pain management in hidradenitis suppurativa. *Semin Cutan Med Surg*. 2017;36(2):75-78. doi:10.12788/j.sder.2017.016
14. Aşkın Ö, Ferhatoğlu ZA, Özkoca D, Cesur SK, Tüzün Y. The comorbidities of hidradenitis suppurativa. *Clin Dermatol*. 2025;43(4):449-454. doi:10.1016/j.clindermatol.2025.05.009
15. Vazquez BG, Alikhan A, Weaver AL, Wetter DA, Davis MDP. Incidence of hidradenitis suppurativa and associated factors: a population-based study of Olmsted County, Minnesota. *J Invest Dermatol*. 2013;133(1):97-103. doi:10.1038/jid.2012.255
16. Aromataris E, Lockwood C, Porritt K, Pilla B, Jordan Z, editors. *JBIM Manual for Evidence Synthesis*. Adelaide: JBI; 2024. doi:10.46658/JBIMES-24-01
17. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;372:n71. doi:10.1136/bmj.n71

Appendices

Appendix I: Search strategy

The following outlines the MEDLINE (via OVID) search strategy, which will be adapted for use in other databases. The search will be conducted in November 2025, limited to English-language studies with no restrictions on publication date.

Table S1 Search strategy

MEDLINE (via OVID)	
Step	Terms
1	hidradenitis suppurativa/
2	(hidradenitis suppurativa or HS or acne inversa or verneuil* disease).mp.
3	1 OR 2
4	(patient perspecti* or patient experien* or patient opinion* or patient attitude* or patient view* or patient-reported outcome* or patient-reported experien* or patient's experience* or lived experience*).mp.

5	(stigma or shame or self management or self-treatment or disengagement or unmet need* or care gap* or self care).mp. or "Health Services Needs and Demand"/ or social stigma/ or shame/ or self-management/ or self care/ or health knowledge, attitudes, practice/
6	("help seeking" or help-seeking or "treatment seeking" or "care seeking" or "health seeking" or health-seeking or "access to care" or "access to healthcare" or "healthcare access" or "health service access" or healthcare utilisation or continuity of care or patient delay* or diagnostic delay* or treatment delay* or delayed diagnosis or late presentation or non-attendance or missed appointment* or dropout or health belief*).mp. or help-seeking behavior/ or patient acceptance of health care/ or health services accessibility/ or healthcare disparit*.mp. or continuity of patient care/ or delayed diagnosis/ or time-to-treatment/ or patient compliance/ or no-show patients/ or patient dropouts/ or attitude to health/ or health behavior/
7	4 OR 5 OR 6
8	3 AND 7

Notes:

- .mp. searches multiple fields Including title, abstract, subject heading, keywords
- The truncation symbol (*) allows variations in word endings

Appendix II: Data Extraction

Table S2 Template for capturing relevant study details

Data Item	Description Notes
Study ID	Author (s), year of publication
Country/Healthcare System	Country where the study was conducted; type of system (public, private, mixed)

Participant characteristics	Age, sex, ethnicity, disease severity, comorbidities; note inclusion of underrepresented groups
Concept	Patient-perceived barriers to healthcare access (psychological, social, structural, knowledge-related); disengagement and self-management strategies
Context	Healthcare level (primary, secondary, specialist dermatological care); urban/rural if relevant
Study Design	Type of study (RCT, cohort, case-control, qualitative, systematic review, opinion/text paper, etc.)
Outcomes	Findings relevant to patient-perceived barriers and the review questions; note subgroups or differences by demographics or context
Additional information	Any special considerations, e.g., methodological limitations, underrepresented populations, novel barriers identified

Table S2 serving as a template for capturing relevant study details. Age and country will be extracted as contextual factors, recognizing that barriers may differ by healthcare system type. The draft extraction form will be piloted on a small subset of studies and refined before full extraction.