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Thematic synthesis of the experiences of people with hidradenitis suppurativa: a systematic review*

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Summary

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Conflicts of interest

L.H. and C.B. currently act as consultants for the University of Oxford on an educational grant funded by Pfizer, unrelated to the submitted work. J.R.I. is Editor-in-Chief of the *BJD*; consultant to UCB Pharma, Novartis and Boehringer Ingelheim; and on advisory boards for Viela Bio and Kymera Therapeutics.

Data availability statement

No data were created or analysed in this study: all data reviewed is from previously published work.

*Plain language summary available online

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Background Although hidradenitis suppurativa (HS) is known to affect quality of life, little summative knowledge exists on how HS impacts people living with the condition.

Objectives To synthesize experiences of people with HS within published qualitative research.

Methods Searches on databases MEDLINE, PsycINFO, Embase and CINAHL were conducted on 17 April 2020. Two independent reviewers screened 5512 publications. Study quality was assessed using the National Institute for Health and Care Excellence quality appraisal checklist for qualitative studies. Thematic synthesis generated descriptive and analytic themes.

Results Fourteen studies were included: four studies fulfilled most quality criteria, eight fulfilled some quality criteria, and two fulfilled few quality criteria. There were three final themes. (i) Putting the brakes on life. The physical, psychological and social consequences of HS resulted in people missing out on multiple life events. This could have a cumulative effect that influences the trajectory of someone's life. (ii) A stigmatized identity: concealed and revealed. People try to conceal their HS, visually and verbally, but this results in anticipation and fear of exposure. Social support and psychological acceptance helped people cope. Connecting to others with HS may have a specific role in preserving a positive self-identity. (iii) Falling through the cracks. Delayed diagnosis, misdiagnosis and lack of access to care were reported. People felt unheard and misunderstood by healthcare professionals, and healthcare interactions could enhance feelings of shame.

Conclusions There need to be improvements to clinical care to allow people with HS to live their life more fully.

What is already known about this topic?

- A James Lind Alliance priority setting partnership for hidradenitis suppurativa (HS) identified 'What is the impact of HS and the treatments on people with HS (physical, psychological, financial, social, quality of life)' as a top research priority of patients and healthcare professionals.
- Understanding experiences of HS can identify areas for future research and areas requiring improvement in clinical care.
- Qualitative metasyntheses can generate new insights beyond findings from individual studies.

What does this study add?

- We show the breadth of physical, psychological and social challenges of living with HS.
- We illustrate the stigma felt by people with HS, how individuals attempt to conceal their condition, and how social support and psychological acceptance can help people cope.
- Early diagnosis, management by multidisciplinary teams, access to social support networks and improved communication with patients about managing HS could lead to improvements in care.

Hidradenitis suppurativa (HS) is a long-term inflammatory skin condition that results in abscesses, usually occurring around the groin, buttocks, breasts and armpits. Prevalence estimates vary from 0.05% to 4.1%, and age of onset is typically in young adulthood.¹ Studies in the USA and Europe have suggested HS disproportionately affects women, whereas a study in South Korea has found male patients to predominate.^{2–6}

HS is often difficult to manage and has limited evidence-based treatment options.⁷ There is evidence of poor quality of life, psychological impact and disability associated with HS.⁸

The James Lind Alliance priority setting partnership for hidradenitis suppurativa identified ‘What is the impact of HS and the treatments on people with HS (physical, psychological, financial, social, quality of life)’ as a top ten research priority of patients and healthcare professionals.⁹ This study goes some way to answering this prioritized research question, and highlights gaps in current knowledge.

The aim of this work is to systematically review the qualitative literature reporting the experiences of people living with HS, as well as to: (i) collate what is known about the experience of people living with HS; (ii) collate what is known about the experience of treatment for HS; and (iii) synthesize the data to offer interpretations of the experiences of people with HS.

Methods

The study protocol was prospectively made publicly available (<https://osf.io/cbnh7/> and <https://www.nottingham.ac.uk/research/groups/cebd/resources/protocol-registration.aspx>). We also made a prospective application and subsequent registration on PROSPERO (CRD42020172037).

Literature search strategy

Searches on MEDLINE, PsycINFO, Embase and CINAHL databases were conducted on 17 April 2020. Terms for HS were searched using free text (hidradenitis and acne inversa) and using the relevant subject heading in each database, with no limit on date. The search was not limited in any other way.

An information specialist (D.G.) helped determine the search strategy, full details of which can be found in Table S1 (see Supporting Information).

Inclusion and exclusion criteria

The review included studies conducted globally in any language. All studies that used a qualitative approach to data collection and analysis were included. No article was excluded based on language. Studies had to be relevant to understanding some aspect of experience for people with HS and could include participants with any severity and of any age or sex. Full text needed to be available, which included research letters but not conference abstracts.

Data screening

After duplicates were removed, two reviewers (L.H. and M.M.) independently screened title and abstract of all studies retrieved. Any discrepancies were discussed, and if the discrepancy could not be resolved a third reviewer (N.L.) was consulted. Two reviewers (L.H. and M.M. or N.L.) independently screened full-text articles. Any discrepancies were discussed and a third reviewer (N.L. or M.M.) was consulted when a discrepancy could not be resolved.

Data extraction

A data extraction form was developed and piloted. Information about study characteristics and study quality was extracted. Study quality was assessed by two reviewers (L.H. and M.M. or N.L. or P.L.) independently using the National Institute for Health and Care Excellence quality appraisal checklist for qualitative studies.¹⁰ Discrepancies were discussed, and a third reviewer (M.M. or N.L.) was consulted when discrepancies were difficult to resolve.

Evidence synthesis

Thematic synthesis involved an iterative three-stepped approach: (i) coding findings line by line to translate the

concepts between studies and begin the process of synthesis; (ii) developing descriptive themes by looking for similarities and differences between codes, and grouping into a hierarchical structure; and (iii) generating analytical themes that interpret findings beyond the present data and answer the review questions.¹¹

Synthesis was performed by L.H. (qualitative methodology and health psychology background). Descriptive themes were secondarily coded by P.L. for five of 14 studies that were purposefully selected to cover a range of topics, study quality and country. There were few discrepancies, but each was discussed and resolved. All authors were included in discussions about the descriptive and analytic themes to ensure interpretation was considered from a variety of perspectives (expertise within the team includes health psychology, sociology, dermatology, nursing, patient experience, applied research and qualitative methodology).

Patient involvement

Patient involvement aimed to aid interpretation of the findings, as well as to assess the acceptability of language and content. K.H-S was asked to read and comment on early versions of analysis and was involved in ongoing discussions and writing. Patient involvement resulted in changing wording that had negative connotations (e.g. replacing 'smell' with 'odour'); it added interpretation to the analysis (e.g. highlighted the language used around the idea of 'acceptance'); and added ideas to include in the discussion (e.g. impact of comorbidities).

Data management

References were stored in an EndNote (Clarivate, Philadelphia, PA, USA) library and uploaded to Rayyan, a web app for systematic reviews (<https://rayyan.qcri.org/>), for data screening. Studies included in the metasynthesis were imported into NVivo 12 (NVivo software; QSR International, Burlington, MA, USA) for coding.

Results

Search results

The PRISMA flow diagram in Figure 1 shows 8820 records were initially identified in searches. Fourteen studies were considered eligible for inclusion in the metasynthesis. Information on the 14 included studies (referred to as Articles 1–14) is provided in Table 1. Participant demographics are reported in Table 2. Not all included studies contain independent data, and Table 2 illustrates which studies used the same dataset. These studies were all included in the metasynthesis, as it was deemed appropriate to include all available data.

Studies were conducted in the USA, Denmark, Ireland and Israel. All articles were written in English. Qualitative data

collection was reported via semistructured interviews in seven studies; via semistructured interviews and focus groups in four studies; via a patient engagement event in one study; by asking a single question in one study; and by reviewing Facebook posts and comments in one study. Of the studies that reported sex, there was a predominance of female over male participation (ratio 3 : 1); of the studies that reported disease severity, there were fewer participants with mild severity; and of the studies that reported age, participant age ranged from 18–4 to 74 years.

Study quality

Overall, four studies were considered to fulfil most of the quality checklist criteria; eight studies were considered to fulfil some of the quality checklist criteria; and two studies were considered to fulfil few of the checklist criteria.¹⁰ Table S2 (see Supporting Information) contains the quality ratings of each article, but notable findings are summarized here. Of the 14 studies included, 12 defined clear aims and/or objectives; 13 reported ethical conduct appropriately; eight used an appropriate research design; nine used reliable methods; 10 used a sufficiently rigorous data analysis process; and 11 provided convincing findings. Lack of reporting in articles resulted in uncertainties in study qualities, notably including being unsure how defensible the methodology was in four studies; unsure how appropriately the data collection was carried out in four studies; how rich the data were in eight studies; and how reliable the analysis was in six studies. Furthermore, only two were judged to describe clearly the role of the researcher; only four were judged to describe clearly the context; and eight did not discuss limitations encountered.

Thematic synthesis results

Descriptive themes

Table 3 outlines the descriptive themes collating the data on living with HS, supported by illustrative quotations. Data are presented in two areas: (i) HS symptoms and the impact of HS and (ii) adjustment to life with HS. Table 4 outlines the descriptive theme collating the data on healthcare and treatment experiences. Analytic themes synthesize the descriptive themes and offer interpretations of the data. The themes 'go beyond' the initial data sources by contextualizing the findings, which was informed by published literature and theory.¹¹

Analytic themes

Theme 1: Putting the brakes on life The symptoms of HS were reported to be, at times, unbearable. While there were many symptoms associated with HS, pain was reported as a central symptom of active disease that can feel both relentless and extreme.

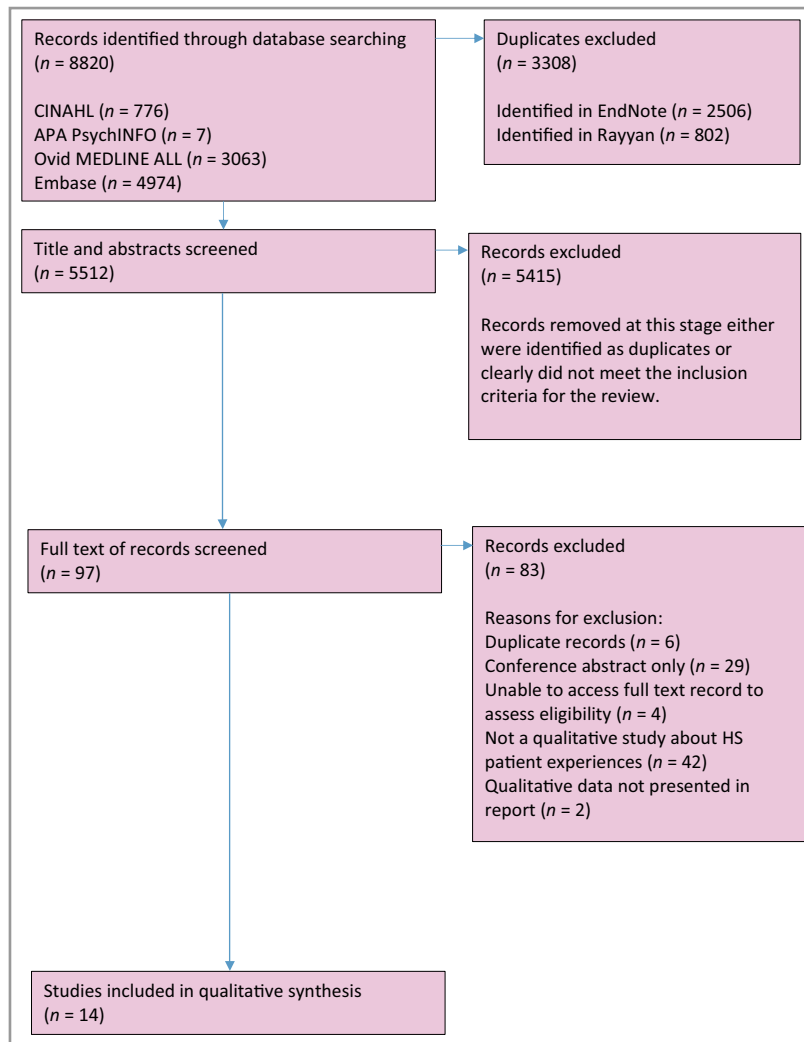


Figure 1 PRISMA flow diagram

‘What happens is the pain increases and then you get to the point where it’s the most unbearable thing you could imagine.’ (Article 3)

The symptoms of HS also affected functioning in multiple ways, making everyday activities a struggle. The symptoms of HS are socially and psychologically challenging. The discharge from the boils can have a strong unpleasant odour, and people reported being keen to avoid embarrassment. They reported avoiding social situations where they feel their HS lesions may be exposed. It was common to read of people retreating to bed and waiting for the flare to subside before they dared to venture out of the house.

‘When I have my flare-ups I just like being in the bed. I can’t stand being around people.’ (Article 4)

The coping strategy of hiding, waiting, and avoiding situations because of both the impact from the symptoms themselves, and the perceived negative reactions from others, seemed to have negative psychological consequences.

‘I have a party tonight. I bought a new dress and have waited so long for this event. But two ugly abscesses have appeared under my chest and armpit, and I can’t lift my arm or wear the dress. This disease won again, one-nil HS. I don’t want to go. All I want to do is stay home in bed and cry. Instead of putting on makeup and styling my hair, I will be busy bandaging myself. Why do I get this? What did I do wrong? Why me? Why now? I feel no hope with HS. It isolates me from everything. I deal only with it all the time, and I am so tired.’ (Article 14)

These periods of avoiding situations such as work or social events may have a cumulative effect. The cumulative life-course impairment is a theoretical construct referring to the nonreversible burden of a chronic skin disease over time that was originally observed in patients with psoriasis.¹² For example, job choices to avoid challenges around functioning can have longer-term career impacts; avoiding first dates can result in not developing relationships or having children; and

Table 1 Study characteristics

Article ID	First author + publication year	Journal name	Article type	Country	Aims/objectives	Setting described	Data collection methods described	Data analysis methods described
1	Keary 2020 ²⁷	British Journal of Dermatology	Full-length article	Ireland	To get a deeper understanding of the lived experience of psychological distress in HS	One secondary care dermatology clinic, large suburban teaching hospital	Semistructured interviews lasting 1–1.5 h	Inductive thematic analysis
2	Kirby 2020 ²⁸	British Journal of Dermatology	Full-length article	USA and Denmark	To develop and test the HSQOL tool, an instrument designed to measure the HS-specific HRQOL of adults with HS in the setting of a clinical trial	Two academic institutions in the USA and Denmark	Semistructured concept elicitation interviews lasting 30–60 min	Grounded theory methods
3	Patel 2020 ³⁴	British Journal of Dermatology	Research letter	USA	To evaluate HS-specific pain using patients' own words	One HS treatment centre	Semistructured interviews on the telephone (duration unknown)	Inductive thematic approach
4	Sarfo 2020 ³⁵	British Journal of Dermatology	Research letter	USA	To explore the patient perspective of an HS flare	Recruited from a research network of four academic health systems in the mid-Atlantic USA	In-depth semistructured interviews and focus groups (duration unknown)	Inductive thematic approach
5	Kimball 2018 ³⁶	Journal of Dermatological Treatment	Full-length article	USA	To develop a comprehensive framework by which potential HS treatment areas could be identified and defined and to develop PRO questionnaires capable of measuring those concepts in HS treatment studies	One clinical dermatology practice in Boston, USA	Face-to-face concept elicitation interviews (approx. 60 min)	Identify and catalogue concepts, analysed for saturation and concept frequency (number of people who mentioned a concept at least once)
6	Esmann 2011 ³⁷	Acta Dermatologica Venereologica	Full-length article	Denmark	To obtain an increased understanding of the psychosocial problems associated with HS and their contexts	Outpatient clinic at one dermatology department	12 interviews lasting 1–1.5 h and 4 focus groups lasting 3 h	Analysis aims at identifying general topics of relevance
7	Thorlacius 2018 ²⁹	British Journal of Dermatology	Full-length article	USA and Denmark	To develop a core outcome set of domains that is relevant to all major stakeholders, including patients, to be recommended for use in all subsequent HS clinical trials	Two secondary care dermatology departments	Semistructured interviews and focus groups	Initially examined for units of meaning, coded as items and grouped into categories
8	Kirby 2016 ³⁰	JAMA Dermatology	Research letter	USA	To explore the coping strategies of people with HS	One dermatology clinic	Semistructured interviews	Inductive thematic analysis

(continued)

Table 1 (continued)

Article ID	First author + publication year	Journal name	Article type	Country	Aims/objectives	Setting described	Data collection methods described	Data analysis methods described
9	Sisic 2017 ³¹	<i>Journal of Cutaneous Medicine and Surgery</i>	Full-length article	USA	To develop a QoL instrument for HS (HS-QoL) in accordance with recommended standards	One dermatology department	Face-to-face semistructured concept elicitation interviews	Thematic analysis
10	Shukla 2020 ³⁸	<i>British Journal of Dermatology</i>	Research letter	USA	To engage patient leaders of support communities for patients with HS on Facebook to identify barriers to seeking clinical care and participating in research	Patient engagement event	One day in-person meeting with HS patient leaders	Rapid thematic analysis and summary of quotations
11	Kirby 2016 ³⁰	<i>JAMA Dermatology</i>	Research letter	USA	To explore patients' experiences with disease symptoms, relating to damage versus 'active' or inflammatory HS lesions	One dermatology department	Semistructured interviews	Inductive thematic analysis
12	Thorlacius 2019 ³³	<i>Skin Appendage Disorders</i>	Full-length article	Denmark	To develop an HS-specific QOL instrument (HISQOL)	One outpatient clinic	15 interviews and 5 focus groups	Interpretative phenomenological analysis
13	Senthinathan 2018 ³⁹	<i>Journal of Dermatological Treatment</i>	Editorial	USA	To help understand the qualitative impact of HS on patients' quality of life	One dermatology clinic	Ask 'What is one of the most stressful things about your HS?' (Not reported if oral or written)	Responses were entered in Wordle, a word cloud application
14	Fisher 2020 ⁴⁰	<i>Archives of Dermatological Research</i>	Full-length article	Israel	To explore the use of a Facebook support group for patients and analyse the contents of shared posts to contribute a deeper understanding of patients' needs and possible ways of engaging them	Online, Facebook group for patients	Review of 715 posts and over 8300 comments from 1 January 2018 to 31 June 2019	Content analysis

HS, hidradenitis suppurativa; HISQOL, Hidradenitis Suppurativa Quality of Life; HRQOL, health-related quality of life; PRO, patient-reported outcome; QoL, quality of life.

Table 2 Participant characteristics

First author + ref. ^a	Esmann ³⁷										
	Keary ²⁷	Kirby, ²⁸ Thorlacius, ²⁹ Kirby, ³⁰ Susic, ³¹ Kirby ³² (USA)	Kirby, ²⁸ Thorlacius, ²⁹ Thorlacius, ³³ (Danish)	Patel ³⁴	Sarfo ³⁵	Kimball ³⁶	Interviews	Focus groups	Shukla ³⁸	Senthilnathan ³⁹	Fisher ⁴⁰
Article ID	1	2, 7, 8, 9, 11	2, 7, 12	3	4	5	6	6	10	13	14
N	12	21	21	15	13	20	12	12	6	25	NR ^b
Age (years)											
Range	24–54	23–74	19–63	NR	31–58	18.5–56.5	NR	NR	NR	NR	NR
Median	NR	NR	NR	44	NR	NR	NR	NR	37.5	NR	NR
IQR	NR	NR	NR	27–50	NR	NR	NR	NR	37–38.75	NR	NR
Mean	NR	46.8	37.9	NR	NR	37.1	NR	NR	NR	NR	NR
SD	NR	13.7	NR	NR	NR	12	NR	NR	NR	NR	NR
Sex, n (%)											
Female	10 (83)	16 (76)	13 (62)	13 (87)	10 (77)	15 (75)	9 (75)	8 (67)	6 (100)	NR	NR
Male	2 (17)	5 (24)	8 (38)	2 (13)	3 (23)	5 (25)	3 (25)	4 (33)	0 (0)	NR	NR
Ethnicity reported, n (%)											
White/Hispanic	NR	16 (76)	21 (100)	8 (53)	6 (46)	10 (50)	NR	NR	NR	NR	NR
Black/African American	NR	2 (10)	0 (0)	7 (47)	4 (31)	6 (30)	NR	NR	NR	NR	NR
Asian	NR	1 (4)	0 (0)	0	0 (0)	0 (0)	NR	NR	NR	NR	NR
Bi/multi/mixed	NR	2 (10)	0 (0)	0 (0)	0 (0)	2 (10)	NR	NR	NR	NR	NR
Other	NR	0 (0)	0 (0)	0 (0)	0 (0)	1 (5)	NR	NR	NR	NR	NR
Missing	NR	0 (0)	0 (0)	0 (0)	3 (23)	1 (5)	NR	NR	NR	NR	NR
Disease duration (years)											
Mean	NR	20.5	19.8	NR	NR	12.9	NR	NR	NR	NR	NR
SD	NR	12.7	10	NR	NR	28	NR	NR	NR	NR	NR
Range	NR	NR	NR	NR	NR	0–12.9	NR	NR	NR	NR	NR
HS for > 10 years	NR	NR	NR	NR	NR	NR	11	NR	NR	NR	NR
HS for 6 years	NR	NR	NR	NR	NR	NR	1	NR	NR	NR	NR
Age at diagnosis (years)											
Median	NR	NR	NR	28	NR	NR	NR	NR	NR	NR	NR
IQR	NR	NR	NR	20.3–45.5	NR	NR	NR	NR	NR	NR	NR
Hurley stage, n (%) ^c											
I (mild)	NR	0 (0)	3 (14)	5 (33)	3 (23)	3 (15)	1 (8)	NR	NR	NR	NR
II (moderate)	NR	12 (57)	12 (57)	5 (33)	5 (39)	11 (55)	7 (58)	NR	NR	NR	NR
III (severe)	NR	9 (43)	6 (29)	5 (33)	5 (39)	6 (30)	4 (33)	NR	NR	NR	NR

NR, not reported; IQR, interquartile range. ^aSome studies contain data from the same set of participants, while one article contained data for multiple sets of participants (interview participants and focus group participants reported separately), so from the 14 included studies, there are 11 sets of participants. ^bAnalysis of comments on Facebook group of nearly 850 members, but no detail on number of people posting comments. ^cThe Hurley staging system is a classification to grade the severity of HS.⁴¹

Table 3 Descriptive themes on experiences of living with hidradenitis suppurativa (HS)

Descriptive themes on living with HS	Illustrative quotations	ID of studies with data on subtheme
Symptoms and impacts		
Physical sensations. People described physical sensations or symptoms of HS. There was clearly one set of symptoms for active disease and another relating to damage from the disease.		
Active disease/flare	“Pain increases dramatically, and this odour goes up big time.” (Article 3)	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 12, 13
Damage/scars	“When something touches it it’s just like pins and needles.” (Article 11)	3, 6, 7, 11, 13, 12
Limits on physical functioning. People described a variety of ways in which their physical functioning or physical ability to do things was affected by their HS symptoms.		
Clothing	“I usually have pain associated with wearing underwear, a bra, or nylons, jeans that initially sets it off, so it’s very hard to wear normal clothes that are casual . . . It limits the type of clothes that I can wear.” (Article 5)	2, 3, 5, 6, 7, 8, 9, 14
Shaving, washing and hygiene	“It’s really hard to poop when you have an active lesion between your buttocks. And not just pooping but then clean up and trying to keep that area clean and sanitized is very hard.” (Article 2)	2, 5, 6, 7, 11, 12
Socializing	“I don’t really go out as much because I am typically in pain and it’s painful to sit and I’m not really interested in socializing with friends and family as much.” (Article 3)	3, 5, 6, 9, 12, 13
Movements, exercise and activities	“There are days when I can’t hold up my arm to tie up my hair, and you know, it’s little things like that or even climbing the stairs, you know.” (Article 1)	1, 3, 4, 5, 6, 7, 9, 10, 11, 12
Work and school	“There’s some times like this last flare-up I couldn’t even work.” (Article 4)	2, 3, 4, 5, 6, 7, 9, 10, 12
Sex	“[Talking about sexual intercourse] And sometimes we just laugh because he has fibromyalgia and I have this. And sometimes we add a little humor because we have to.” (Article 8)	1, 5, 6, 7, 8, 9, 12
Sleep	“When I had that I could maybe fall asleep for a little bit but if I would move in my sleep it would wake me right up.” (Article 2)	2, 3, 5, 7, 12
Attending appointments	“. . . but the often unendurable pain and itching from developing lesions may also lead patients to cancel appointments.” (Article 6)	6, 12
Psychological impact. People described a variety of ways their thoughts and feelings were impacted by HS symptoms.		
Impacting concentration	“. . . if it’s painful, just trying to concentrate on something else other than the pain because the pain of hidradenitis is not something you can just ignore.” (Article 5)	3, 5, 7, 9
Impacting mood	“It became a nightmare. I was suffering physically and emotionally.” (Article 10)	6, 9, 10, 14
Low mood and suicidal thoughts	“I feel like if you have HS you just don’t feel like yourself. And it’s depressing because you want to be like yourself. And me personally, I feel depressed because of this most of the time.” (Article 2)	1, 2, 4, 5, 6, 7, 9, 10, 12, 13
Irritability and anger	“It feels more irritating and more invasive . . . when it gets bigger, it feels like it’s – it’s bothering me more . . . irritating . . . It can be irritating . . . And because they’re irritating, you want to get rid of them . . . just because it’s that aggravating . . .” (Article 5)	3, 4, 5, 6, 7, 9, 12

(continued)

Table 3 (continued)

Descriptive themes on living with HS	Illustrative quotations	ID of studies with data on subtheme
Anxiety, worry and guilt	“It’s more the mental aspect of either feeling like I’m not being a good father or being a good husband ... or feeling like, you know – we can’t go on a vacation because of my condition.” (Article 5)	4, 5, 6, 7, 12
Lack of control	“It lasted a fortnight; I was totally helpless.” (Article 6)	1, 2, 3, 5, 6, 7, 10, 12, 14
Lack of self-worth	“So just kind of really it really messes with your self-esteem ... it’s difficult. Like I said, it wears on your self-esteem because it’s not something that’s easy to explain.” (Article 5)	1, 5, 6, 7, 8, 9, 10, 11, 12
Adjusting to life with HS		
Challenges. People described several ways in which they found living with HS to be socially challenging.		
Perceived and anticipated negative reactions	“[I’d be concerned] that they’d have the similar reaction, the disgust of it, and then pity, and then “why aren’t you doing anything about it?” (Article 1)	1, 2, 3, 5, 6, 7, 10, 11, 12
Hiding and avoiding	“I just didn’t want anyone to see me so I just isolated myself rather than having to explain it I guess.” (Article 1)	1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 12, 14
Feeling alone	“My two sisters had the same thing and didn’t speak about HS because they were too embarrassed. It’s an isolating and debilitating disease.” (Article 10)	1, 6, 7, 9, 10, 12, 14
Affecting relationships	“I’m to the point right now where my marriage is falling apart ... My husband has just had enough.” (Article 5)	1, 5, 6, 7, 9, 12, 13
Facilitators. People described what helped them cope with living with HS.		
Attempts at acceptance or positive thinking	“I’ve had to do a lot of soul searching and pep talks and say well in spite of these scars ... you still look good. You still can think highly of yourself and still be sexy. You just have to wear different underwear certain days of the week but that’s ok.” (Article 8)	3, 4, 5, 8, 12
Opening up and careful disclosure	“I told my friend ... and he was so cool about it. He’s like “hey that’s ok. That’s something that you took your time to tell us, that’s fine.” ... And I got two different positive reactions.” (Article 8)	1, 6, 7, 8
Connecting with others with HS	“Having that support there, that’s what really helped me through it ... And because I could talk to them about it as well because they knew what was going on because ... they’ve seen the sores, they knew I was in an awful lot of pain.” (Article 1)	1, 6, 10, 12, 14
Supportive relationships	“It has helped [sharing their condition with someone else], and I’ll tell you for sure, that it has helped that my girlfriend is educated too. It would be harder to explain something like this to a person who doesn’t want to read about it and understand it.” (Article 8)	1, 6, 7, 8, 9, 10, 12

avoiding socializing can isolate people from friends and family, and impact mental health.

‘Patients generally look at dating as troublesome, because they find the situation with disgusting lesions too complicated and too difficult to explain, and this

makes them push people away. “Usually, I have no problems talking with people, but in such situations I simply shut people off.” A patient reports with regret that she has realized that “I am not going to marry anyone and in any case I am not going to have children.” (Article 6)

Table 4 Descriptive themes on experiences of treatment for hidradenitis suppurativa (HS)

Descriptive themes on living with HS	Illustrative quotations	ID of studies with data on subtheme
Healthcare and treatment experiences		
Access to information. People mostly described a lack of knowledge among healthcare professionals about HS. There were a few descriptions of knowledgeable healthcare practitioners who had helped them manage the condition.		
Healthcare professional knowledge	“It’s so rare to see a doctor who knows about HS.” (Article 10)	5, 6, 7, 9, 10, 12
Delays and misdiagnosis	‘They were all treated for years by clinicians who were apparently unaware of the diagnosis. Their lesions were treated as temporary symptoms and they had no explanation of repeated lesions, e.g. “why should I visit five dermatologists before I got an explanation”.’ (Article 6)	3, 6, 9, 10
Limited access to services	“Getting in to see a dermatologist is like getting to see the president.” (Article 10)	6, 9, 10, 14
Relationship with healthcare services. People described challenges they had faced when interacting with healthcare services and healthcare professionals and their perceptions of the service. There were a few reports of supportive relationships involving open communication.		
Feeling unheard or unsupported by healthcare professionals	“Doctors have problems with listening. [Doctors] think they are experts and are unwilling to listen to our preferences.” (Article 10)	1, 5, 6, 7, 10, 12
Distrust	“Distrust of doctors is rampant . . . People say I don’t trust the medical field.” (Article 10)	10
Disengagement from services	‘Many reported feeling angry because they felt that their doctors were being dismissive, which made them want to disengage from medical services.’ (Article 1)	1, 10
Going online	‘Many spoke about online forums for people with HS. There were both advantages and disadvantages associated with these forums. The advantages were increased support and access to advice. The disadvantage given was that it would be distressing for people newly diagnosed as it could show how severe the condition could become.’ (Article 1)	1, 10, 14
Treatment experiences. People described the experiences of seeking treatment, learning to manage the condition, concerns about treatment and the burdens of treatment.		
From seeking a cure to accepting no cure	“Can I get rid of it so that it won’t come back at all . . .” (Article 5)	1, 5, 6, 14
Concern about the effectiveness of treatment	‘Sadness and worry also occur when patients . . . if the disease is unaffected by the treatment provided.’ (Article 6)	2, 6, 7, 8, 10, 12, 14
Self-management burden – caring for wounds, managing weight and smoking	“Instead of putting on makeup and styling my hair, I will be busy bandaging myself.” (Article 14)	1, 6, 7, 12, 14
Burden on time	‘Time spent on treatment’ (Article 12)	7, 12, 14
Concern about side-effects or symptoms from treatments	‘Concern about medication and side-effects’ (Article 9)	7, 9, 12
Financial burden	“I’ve spent hundreds and hundreds of dollars a month in, um, co-pays, stupid treatments that I was told to try again that didn’t work in the first place, because nobody believes me . . . Just the overall financial burden of what’s happened to me.” (Article 5)	5, 6, 7, 9

While the majority of articles covered the impact of active HS, there were findings in some articles that acknowledged the impact of the damage left even when lesions were no longer active.

Theme 2: A stigmatized identity: concealed and revealed People with HS reported an acute awareness of a stigma of HS. Goffman¹³

describes a stigma as ‘an attribute that is deeply discrediting’; however, he warns that the attribute is not problematic in isolation but within relationships and social contexts.¹⁴

In terms of negative impact, people reported going to great lengths to visually conceal their symptoms (both active symptoms and scars) from others, for example by wearing clothing to cover up the HS lesions. During active phases of

the condition, they also attempted to conceal the odour. Compared with other skin conditions, HS appears to be relatively concealable. This could suggest HS is a 'concealable stigmatized identity', namely an identity that can be hidden from others, and that is socially devalued and negatively stereotyped.¹⁵

However, it is not entirely concealable, and participants reported worrying that pus would leak and stain clothes, or that others would notice an odour. Therefore, rather than offer freedom from the effects of stigma, the concealable nature of the lesions resulted in ambiguity, anticipation of exposure, constant checking of other people's reactions and avoidance of situations.¹⁵

'I'll take any pain but oh God, don't let anything happen to me like ... have an accident in public or something would burst ... that would just be the end of me. If something like that was to happen ... I could be housebound for a good while because the thoughts of it would probably be ... I couldn't imagine. Yeah, that would be the worst thing for me, it would be the embarrassment and the shame of ... oh my God. (Article 1)

People reported ways of coping. There were examples of how people had maintained or re-established a positive self-identity, using positive self-talk, acceptance and not paying attention to it. There appeared to be a trend of finding it more challenging during younger years, with some reflecting that they had found ways to accept themselves over time.

'I've had to do a lot of soul searching and pep talks and say well in spite of these scars ... you still look good. You still can think highly of yourself and still be sexy. You just have to wear different underwear certain days of the week but that's ok.' (Article 8)

Disclosing and discussing their condition with others, be that family, friends, partners, healthcare professionals or others with HS, helped individuals feel supported or understood. People were careful about who they spoke to, and it was important that the person respond supportively for this disclosure to offer benefits.

'I told my friend ... and he was so cool about it. He's like "hey that's ok. That's something that you took your time to tell us, that's fine." ... And I got two different positive reactions.' (Article 8)

Social identity theory and self-categorization theory suggests individuals try to maintain self-esteem by viewing their ingroup favourably.^{16,17} In the case of stigmatized identities, such as HS, where individuals often have low self-worth, it is not always possible to view the ingroup favourably.¹⁴ One strategy that can increase self-worth is to strengthen a collective identity.¹⁴ This may explain why people with HS expressed a desire to speak to others with HS, seek online support groups, and reported benefits of

connecting with other people with HS. These support networks may have the distinct benefit of maintaining a positive self-identity.

'Having that support there, that's what really helped me through it ... And because I could talk to them about it as well because they knew what was going on because ... they've seen the sores, they knew I was in an awful lot of pain.' (Article 1)

This suggests a paradox: people with HS cope by hiding their condition, both verbally and visually, but this situation makes it difficult to adjust psychologically to living with HS in the longer term.

Theme 3: Falling through the cracks Findings suggest that healthcare was frequently falling short of participants' expectations and needs. Participants reported a lack of knowledge about HS amongst healthcare professionals, and there is limited access to healthcare professionals who understand HS. These problems can lead to delays in diagnosis or to misdiagnosis, which can result in irreversible tissue damage due to the scarring nature of the condition.^{18,19}

Another way that people with HS appeared to be 'falling through the cracks' of healthcare systems is that they often reported feeling misunderstood, unheard and dismissed by professionals, which in some cases may lead to mistrust and disengagement with services. The stigmatized identity, lack of sense of personal control over HS and low self-worth may be important factors that mean poor or unclear communication from healthcare professionals can easily lead to a breakdown in therapeutic relationships.

'I used to bawl my eyes out. I used to cry. You know, you'd come back after going to the doctors and you cry because they just don't realise.' (Article 1)

Like other long-term conditions that cannot be cured, HS needs to be managed. People reported finding this challenging to accept and come to terms with.

'I suppose the chronic aspect of it was a bit of a shock to me because I thought that this is a boil, this is an abscess ... you know, I'll have it treated it will be gone. And then you learn, no this will go on for decades.' (Article 1)

People reported not feeling adequately supported in managing the condition. HS involves self-management (e.g. bandages, pain relief, managing weight, etc.), as well as ongoing topical and oral medication or surgery where there are some concerns about the effectiveness and side-effects of the treatments. Discussions about weight management and stopping smoking, which are advised by healthcare professionals to improve self-management of HS, were particularly challenging for participants. They reported that healthcare professionals advise these changes without understanding the challenges for the individual, leaving people feeling stigmatized and 'dehumanized'.

For some participants who identified themselves as overweight, there was another source of shame. They reported that medical professionals told them to lose weight without realizing how difficult this was for them. They maintained that this emphasized their sense of shame about being overweight (Article 1).

Discussion

There were 14 studies included in our metasynthesis, which illustrated multiple challenges individuals face in living with HS and in seeking treatment and support. All studies eligible for inclusion were published within the last decade, which mirrors a general trend towards increased publication in HS research over the period, and the development of new treatments for the condition.^{20,21}

Diagnostic delay of HS is recognized as a global problem, with one international study across 24 countries showing patients with HS had an average diagnostic delay of 7.2 years compared with an average diagnostic delay of 1.6 years for patients with psoriasis.²² A German study found that a longer delay in HS diagnosis was associated with greater disease severity, an increased number of surgically treated sites, concomitant diseases, and a higher number of days of work missed.¹⁸ This review highlights how diagnostic delay can leave individuals feeling unheard and unsupported, potentially leading to mistrust of the medical community, and disengagement with healthcare services.

'Falling through the cracks' of healthcare services has a human cost. A cohort study using the Danish national register suggests people with HS are at an increased risk of death by suicide compared with people without HS.²³ Many of the consequences of HS within the qualitative literature mirror the statistical data available on the impact of HS on quality of life, psychological wellbeing, sex life and disability.^{8,24}

Some of these impacts, such as psychological impacts, low self-esteem and high levels of felt stigma, are also seen across other skin conditions.²⁵ This review suggests that the concept of 'cumulative life-course impairment', which was developed in the psoriasis literature, is relevant to patients with HS, with the consequences of the disease having compounding impacts that can change the life course of an individual, and it advocates for early intervention where possible.¹² A key difference between HS and other skin conditions is the often progressive nature of HS, as opposed to the typically relapsing and remitting nature of others such as eczema and psoriasis; furthermore, HS lesions often leave irreversible scars.¹⁹

There are limitations to this work. Reporting of studies was frequently incomplete, which often led to uncertainty of study quality. This is likely because five of the 14 studies were research letters/editorials and, of the eight full-length articles, five were reporting qualitative analysis within a wider outcome measure development project. Adequate reporting of qualitative methods and results is required for readers to assess the credibility and transferability of the data.²⁶ Solutions include journal editors offering full article publication for

substantial qualitative studies, use of supplementary materials or making details available on publicly accessible data-sharing websites.

Included studies came from just four countries (USA, Denmark, Ireland and Israel); participants typically had more severe HS and were largely white. The data on healthcare and treatment experiences (theme 3) were sparser than for the other themes. The data collated are limited by research available but the review team did not search the grey literature, which may have contained data missing within this review.

The experience of managing HS alongside other comorbidities was not reported in the qualitative literature reviewed. Because HS is associated with several other conditions (including inflammatory bowel disease, inflammatory arthritis, pilonidal sinus, polycystic ovary syndrome, Down syndrome, obstructive sleep apnoea and pyoderma gangrenosum), many people will be living with HS alongside other conditions.¹ Interactions of managing more than one long-term condition can have additional challenges that need to be acknowledged.

Given that the onset of HS is known to occur typically at around puberty, the experience of younger people with HS is largely missing, as of the articles that reported age of participants, the youngest was 18 years old. Understanding the experiences of young people living with HS is currently a gap in the literature.

Future research directions must address development, evaluation and implementation of interventions to address the needs of people with HS. The results of this review will be useful for informing the content of interventions. Interventions to address doctor-patient communication may be required. Observing the communication between healthcare professionals and patients with HS may offer useful insights on this. Interventions to improve the diagnosis of HS among general practitioners/family doctors are required.

Future qualitative studies focusing on the experiences of healthcare and treatment of HS are needed. While some experiences of living with HS will be universal across countries, differences in healthcare systems and societal attitudes mean it is important to recognize there may be crucial differences in experiences by country, and so qualitative studies exploring experiences in different countries would be beneficial.

Grounded in the key challenges this review has highlighted, we have proposed the following four key recommendations to improve HS management that we feel may improve patient experiences of healthcare for their HS.

(i) *Early diagnosis is essential*: delayed diagnosis, lack of healthcare professional knowledge and limited access to services needs addressing. Early intervention is key to improving the lives of people living with HS and educational materials for diagnosis of HS should be developed, evaluated and implemented, aimed at both primary and secondary care clinicians.

(ii) *A multidisciplinary team approach is needed*: the impact of HS is physical, psychological and social. HS management and research should be based on a biopsychosocial model of health addressing all impacts of the condition. This could be achieved with multidisciplinary teams, and the provision of

psychological and social interventions alongside pharmacological and surgical interventions.

(iii) *Patients need access to social support networks:* additional provision of social support groups for those with HS may help them overcome the negative effects associated with stigmatization, and help them adjust to living with HS. Clinicians should signpost to local and national support groups.

(iv) *Improved communication with patients is essential:* there is a need for improved communication between people with HS and healthcare professionals, particularly for having conversations about the emotional impact of the condition and the behaviour changes such as smoking and weight management, which patients report as challenging. This may be achieved through appropriate training for healthcare professionals.

In conclusion, the expressed experiences of people with HS suggest that this is a challenging condition to live with. It can have profound psychological and social impacts on an individual, impair physical functioning, and impact multiple aspects of their daily life. Social support and psychological acceptance appear to be coping strategies that facilitate adjustment to living with HS, but there need to be changes in the delivery of healthcare, with adequate psychological and social support, to enable people with HS to live their life more fully.

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website:

Table S1 Search strategy.

Table S2 Study quality appraisals.