Thematic synthesis of the experiences of people with Hidradenitis Suppurativa: a systematic review.

L Howells[1] (ORCID: 0000-0003-4157-7394); N Lancaster[2] (ORCID: 0000-0001-5322-345X); M McPhee[1]; C Bundy[3] (ORCID: 0000-0002-5981-3984); J Ingram[4] (ORCID: 0000-0002-5257-1142); P Leighton[1](ORCID: 0000-0001-5208-0274); K Henaghan-Sykes[5]; K S Thomas[1] (ORCID 0000-0001-7785-7465).

[1] Centre of Evidence Based Dermatology, School of Medicine, University of Nottingham, Nottingham

[2] Barnsley Hospital NHS Foundation Trust, Barnsley

[3] School of Healthcare Sciences, University of Cardiff, Cardiff

[4] Division of Infection & Immunity, Cardiff University, Cardiff

[5] Patient partner, Southampton

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Conflicts of interest:

LH and CB currently act as consultants for the University of Oxford on an educational grant funded by Pfizer, unrelated to the submitted work. JRI: Editor-in-Chief of BJD; consultant to UCB Pharma, Novartis and Boehringer Ingelheim; advisory boards for Viela Bio and Kymera Therapeutics.

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Abstract

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.

Aim: to synthesise experiences of people with HS within published qualitative research.

Methods: Searches on databases MEDLINE, PsycINFO, EMBASE and CINHAL were conducted on 17th April 2020. Two independent reviewers screened 5512 publications. Study quality was assessed using the National Institute for Health and Care Excellence (NICE) 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 studies fulfilled some quality criteria, and two studies fulfilled few quality criteria. There were three final themes. ***1) 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. ***2) A stigmatised identity: concealed and revealed –*** People try to conceal their HS, visually and verbally, but this results anticipation and fear of exposure. Social support and psychological acceptance helped people cope. Connection with others with HS may have a specific role in preserving a positive self-identity. ***3) 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 needs to be improvements to clinical care to allow people with HS to live their life more fully.

What's already known about this topic?

- A James Lind Alliance priority setting partnership for 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 ten 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 meta-syntheses can generate new insights beyond findings from individual studies.

What does this study add?

- Demonstrates the breadth of the physical, psychological, and social challenges of living with HS.
- Illustrates 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.
- Suggests early diagnosis, management by multidisciplinary teams, access to social support networks and improved communication about managing HS with patients could lead to improvements in care.

Background

Hidradenitis Suppurativa (HS) is a long-term inflammatory skin condition that results in abscesses which usually occur around the groin, buttocks, breasts and armpits. Prevalence estimates vary between 0.05% and 4.1% [1]. Age of onset of HS is typically in young adulthood (Ingram, 2020). Studies in the USA and Europe have suggested HS disproportionally affects females, whereas a study in South Korea has found higher rates in males [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 prioritised research question and highlight gaps in current knowledge.

Aim: to systematically review the qualitative literature reporting the experiences of people living with HS.

Objectives: 1) to collate what is known about the experience of people living with HS; 2) to collate what is known about the experience of treatment for HS; 3) to synthesis the data to offer interpretations of the experiences of people with HS.

Methods

The study protocol was made publicly available prospectively (https://osf.io/cbnh7/; 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 CINHAL databases were conducted on 17th 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 (DG) helped determine the search strategy, full details of which can be found in the supplementary materials.

Inclusion/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 of any age, gender or severity. Full text needed to be available, which included research letters but not conference abstracts.

Data screening

After duplicates were removed, two reviewers (LH and MP) independently screened title and abstract of all studies retrieved. Any discrepancies were discussed, and if the discrepancy could not be resolved a third reviewer (NL) was consulted. Two reviewers (LH and MP or NL) independently screened full-text articles. Any discrepancies were discussed and a third reviewer (NL or MP) 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 were extracted. Study quality was assessed using the National Institute for Health and Care Excellence (NICE) quality appraisal checklist for qualitative studies by two reviewers (LH and MP or NL or PL) independently [10]. Discrepancies were discussed and a third reviewer (MP or NL) was consulted when discrepancies were difficult to resolve.

Evidence synthesis

Thematic synthesis involved an iterative three stepped approach; 1) coding findings line by line to translate the concepts between studies and begin process of synthesis, 2) developing descriptive themes by looking for similarities and differences between codes and grouping into a hierarchical structure, and 3) generating analytical themes that interpret findings beyond the present data and answer the review questions [11].

Synthesis was performed by LH (qualitative methodology and health psychology background). Descriptive themes were secondary coded by PL for 5/14 studies that were purposefully selected to cover a range of topics, study quality and country. There were few discrepancies, but discrepancies were 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 assess the acceptability of language and content. KS 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’), 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 library and uploaded to https://rayyan.qcri.org/ for data screening. Studies included in the meta-synthesis were imported into NVivo 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 meta-synthesis. Table 1 provides information on the studies included in the meta-synthesis (n=14). Participant demographics are reported in Table 2. Not all studies included in the meta-synthesis contain independent data, and Table 2 illustrates which studies used the same dataset. These studies were all included in the meta-synthesis, as it was deemed appropriate to include all available data.

Studies were conducted in USA, Canada, Denmark, Ireland and Israel. All articles were written in English. Qualitative data collection was reported via semi-structured interviews in seven studies, via semi-structured 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. Out of the studies that report sex, there was a predominance of female participation over males (ratio 3:1). Out of the studies that report disease severity, there were fewer participants with mild severity. Out of the studies that reported age, the 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 S1 in Supplementary Materials contains the quality ratings of each article, but notable findings are summarised here. Out of the 14 studies included, 12 studies 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 clearly describe the role of the researcher, only four were judged to clearly describe 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 quotes. Data is presented in two areas: 1) HS symptoms and the impact of HS and 2) adjustment to life with HS. Table 4 outlines the descriptive theme collating the data on healthcare & treatment experiences. Analytic themes synthesise the descriptive themes and offer interpretations of the data. The themes 'go beyond' the initial data sources by contextualising 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. Whilst there were many symptoms associated with HS, pain was reported as a central symptom of active disease; that can feel both relentless and extreme.

> *'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 every day activities challenging. 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 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, 1:0 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 non-reversible burden of a chronic skin disease over time that was originally observed in psoriasis patients [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 avoiding socialising 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)*

Whilst 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 stigmatised identity: concealed and revealed

People with HS reported an acute awareness of a stigma of HS. Goffman [13] describes a stigma as "an attribute that is deeply discrediting" but warns that the attribute is not problematic in isolation but within relationships and social contexts [14].

Negative impact

People reported going to great lengths to visually conceal their symptoms from others (both active symptoms and scars). 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 to other skin conditions, HS appears to be relatively concealable. This could suggest HS is a ‘concealable stigmatised identity’, which are identities that can be hidden from others and that are socially devalued and negatively stereotyped [15].

However, it is not entirely concealable, and participants reported worrying that pus will leak, and stain clothes, or others will 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)*

Finding ways to cope

There were examples of ways people had maintained or re-established a positive self-identity. People utilised 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 the person responds 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 2 different positive reactions.” (Article 8)*

Social identity theory and self-categorisation theory suggests individuals try to maintain self-esteem by viewing their ingroup favourably [16,17]. In the case of stigmatised 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 with others with HS, seek online support groups, and reported benefits of connecting with other people with HS. These support networks may have a distinct benefit to maintain 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, where people with HS cope by hiding their condition, both verbally and visually, but this situation makes it difficult to psychologically adjust 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 mis-diagnosis, 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 stigmatised 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 break down 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 for people 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 stigmatised and 'dehumanised'.

> *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 a meta-synthesis, which illustrated multiple challenges individuals face 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 last decade and the development of new treatments for the condition [20,21].

Diagnostic delay of HS is recognised as a global problem, with one international study across 24 countries showing HS patients had an average diagnostic delay of 7.2 years compared to psoriasis patients having an average diagnostic delay of 1.6 years [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 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.

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

Strengths and limitations

Reporting of studies was frequently incomplete, which often led to uncertainty of study quality. This is likely due to 5/14 studies being research letters/editorials and 5/8 of the full-length articles 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), and participants typically had more severe HS and were largely white. The data on healthcare and treatment experiences (theme 3) was sparser than other themes. The data collated are limited by research available, however 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. Given 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 HS is known to typically have onset around puberty, the experience of younger people with HS is largely missing, as out of the articles that reported age of participants, the youngest participant was 18 years old. Understanding the experiences of young people living with HS is currently a gap in the literature.

Future research directions

Development, evaluation, and implementation of interventions to address the needs of people with HS is now required. 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 HS patients may offer useful insights on this. Interventions to improve the diagnosis of HS amongst general practitioners/family doctors are required.

Future qualitative studies focussing on the experiences of healthcare and treatment of HS are needed. Whilst some experiences of living with HS will be universal across countries, differences in healthcare systems and societal attitudes mean it is important to recognise 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 that this review has highlighted, we have proposed four key recommendations to improve HS management that we feel may improve patient experiences of healthcare for their HS:

1. **EARLY DIAGNOSIS**

   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.

2. **A MULTIDISCIPLINARY TEAM APPROACH**

   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.

3. **ACCESS TO SOCIAL SUPPORT NETWORKS**

   Additional provision of social support groups for people with HS may help people overcome the negative effects associated with stigmatisation and help people adjust to living with HS. Clinicians should signpost to local and national support groups.

4. **COMMUNICATION WITH PATIENTS**

   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.

Conclusions

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 needs 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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Figure 1 PRISMA Flow Diagram

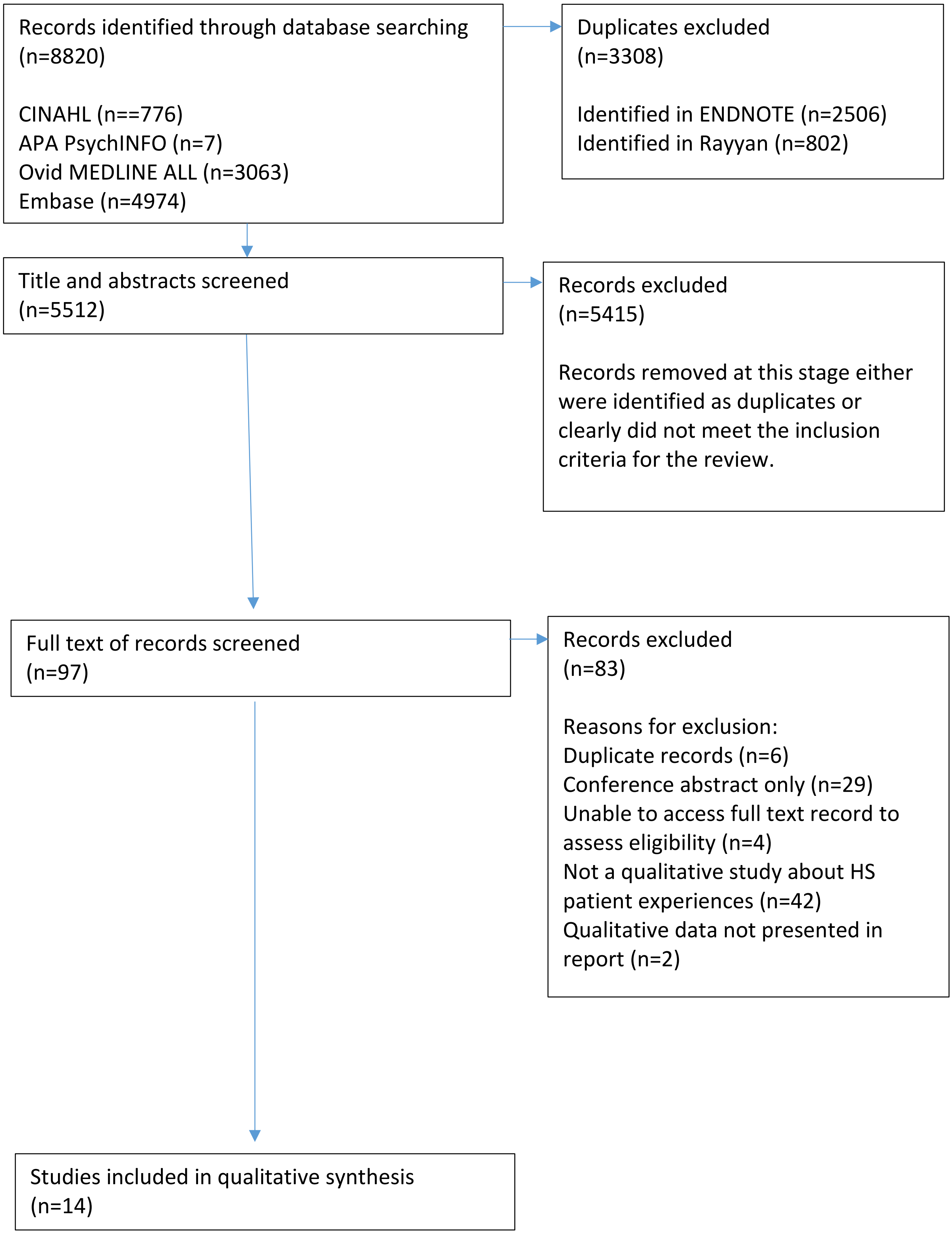

Table 1 Study Characteristics

Article ID	Authors and year of publication	Journal of publication	Article Type	Country	Aims/objectives	Setting described	Data collection methods described	Data analysis methods described
1	Keary et al. (2020)	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.	Semi-structured interviews lasting between 1-1.5 hours.	Inductive thematic analysis
2	Kirby et al. (2020)	British Journal of Dermatology	Full-length article	USA and Denmark	To develop and test the Hidradenitis Suppurativa Quality of Life (HiSQOL) 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	Semi-structured concept elicitation interviews lasting between 30-60 mins.	Grounded theory methods
3	Patel et al. (2020)	British Journal of Dermatology	Research letter	USA	To evaluate HS specific pain using patients' own words.	One HS treatment centre	Semi-structured interviews on the telephone (duration unknown).	Inductive thematic approach
4	Sarfo et al. (2020)	British Journal of Dermatology	Research letter	USA	To explore the patient perspective of a HS flare.	Recruited from a research network of four academic health systems in the mid-Atlantic USA	In depth semi-structured interviews and focus groups (duration unknown).	Inductive thematic approach
5	Kimball et al. (2018)	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	One clinical dermatology practice in Boston.	Face to face concept elicitation interviews (approx. 60 minutes).	identify and catalogue concepts, analysed for saturation and concept frequency (number of subjects who mentioned a

					measuring those concepts in HS treatment studies.			concept at least once)
6	Esmann and Jemec (2011)	Acta Dermato-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 to 1.5 hours and 4 focus groups lasting 3 hours.	Analysis aims at identifying general topics of relevance.
7	Thorlacius et al. (2018b)	British Journal of Dermatology	Full-length article	USA and Denmark	To develop a core outcome set (COS) 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.	Semi-structured interviews and focus groups	Initially examined for units of meaning, coded as items and grouped into categories
8	Kirby et al. (2016)	JAMA Dermatology	Research letter	USA	To explore the coping strategies of individuals with HS.	One dermatology clinic.	Semi-structured interviews	Inductive thematic analysis
9	Sisic et al. (2017)	Journal of Cutaneous Medicine and Surgery	Full-length article	USA	To develop a QoL instrument for HS (HS-QoL) in accordance with recommended standards.	One dermatology department.	Face to face semi-structured concept elicitation interviews.	Thematic analysis
10	Shukla et al. (2020)	British Journal of Dermatology	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.	A patient engagement event	One day in-person meeting with HS patient leaders.	Rapid thematic analysis and summary of quotations
11	Kirby (2016)	J A Acad Dermatol	Research letter	USA	To explore HS patients' experiences with disease symptoms, relating to damage versus 'active' or inflammatory HS lesions.	One dermatology department.	Semi-structured interviews	Inductive thematic analysis

12	Thorlacius et al. (2019)	Skin Appendage Disorders	Full-length article	Denmark	To develop an HS-specific QOL instrument (HiSQOL, Hidradenitis Suppurativa Quality of life).	One outpatient clinic.	15 interviews and 5 focus groups	Interpretative phenomenological analysis
13	Senthilnathan et al. (2018)	Journal of Dermatological Treatment	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 verbally or written)	Responses were entered in Wordle, a word cloud software.
14	Fisher et al. (2019)	Archives of Dermatological Research	Full-length article	Israel	to explore the use of a Facebook support group for HS patients and analyse the contents of shared posts to contribute a deeper understanding of HS patients' needs and possible ways of engaging them.	Online, Facebook Group for HS patients	Review of 715 posts and over 8300 comments between 1 January 2018 to 31 June 2019	Content analysis

Table 2 Participant Characteristics

Authors & year*		Keary, et al. [27]	Kirby, et al. [28], Thorlacius, et al. [29], Kirby, et al. [30], Sisic, et al. [31], Kirby [32] *(USA participants)*	Kirby, et al. [28], Thorlacius, et al. [29], Thorlacius, et al. [33] *(Danish participants)*	Patel, et al. [34]	Sarfo, et al. [35]	Kimball, et al. [36]	Esmann and Jemec [37] *(Interviews)*	Esmann and Jemec [37] *(Focus groups)*	Shukla, et al. [38]	Senthilnathan, et al. [39]	Fisher, et al. [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**
Age (years)	**Range**	24-54	23-74	19-63	NR	31-58	18.5-56.5	NR	NR	NR	NR	NR
	Interquartile range	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
	Median	NR	NR	NR	44	NR		NR	NR	37.5	NR	NR
	Standard deviation	NR	13.7	NR	NR	NR	12	NR	NR	NR	NR	NR
Sex, n (%)	**Female**	10	16	13	13	10	15	9	8	6	NR	NR
	Male	2	5	8	2	3	5	3	4	0	NR	NR
Ethnicity reported, n (%)	**White/Hispanic**	NR	16	21	8	6	10	NR	NR	NR	NR	NR
	Black/African American	NR	2	0	7	4	6	NR	NR	NR	NR	NR
	Asian	NR	1	0	0	0	0	NR	NR	NR	NR	NR
	Bi/multi/mixed	NR	2	0	0	0	2	NR	NR	NR	NR	NR
	other	NR	0	0	0	0	1	NR	NR	NR	NR	NR
	missing	NR	0	0	0	3	1	NR	NR	NR	NR	NR
Disease duration	**mean**	NR	20.5	19.8	NR	NR	12.9	NR	NR	NR	NR	NR
	Standard deviation	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 over 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	**Median**	NR	NR	NR	28	NR	NR	NR	NR	NR	NR	NR
	Interquartile range	NR	NR	NR	20.3-45.5	NR	NR	NR	NR	NR	NR	NR
Disease severity* **	**Hurley stage I (mild)**	NR	0	3	5	3	3	1	NR	NR	NR	NR
	Hurley stage II (moderate)	NR	12	12	5	5	11	7	NR	NR	NR	NR
	Hurley stage III (severe)	NR	9	6	5	5	6	4	NR	NR	NR	NR

NR=not reported

*Some studies contain data from the same set of participants, whilst 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.

**Analysis of comments on Facebook group of nearly 850 members, but no detail on number of people posting comments.

***The Hurley staging system is a classification to grade the severity of HS [41].

Table 3 Descriptive themes on experiences of living with HS

DESCRIPTIVE THEMES ON LIVING WITH HS	**Illustrative quotes**	**Studies with data on sub-theme**
1.HS symptoms and impacts		
1.1 Physical sensations People described physical sensations or symptoms of HS. It was clear there has a set of symptoms for active disease and another set of symptoms relating to damage from the disease.		
1.1.1 Active disease/flares	*"Pain increases dramatically, and this odour goes up big time." (Article 3)*	1,2, 3, 4, 5, 6, 7,8 ,9, 10, 12, 13
1.1.2 Damage/scars	*"When something touches it it's just like pins and needles." (Article 11)*	3, 6, 7, 11, 13, 12
1.2 Limits on physical functioning People described a variety of ways that their physical functioning and ability to physically do something was affected by their HS symptoms.		
1.2.1 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
1.2.2 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
1.2.3 Socialising	*"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
1.2.4 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
1.2.5 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
1.2.6 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
1.2.7 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
1.2.8 Attending appointments	*"but the often unendurable pain and itching from developing lesions may also lead patients to cancel appointments." (Article 6)*	6, 12
1.3 Psychological impact People described a variety of ways their thoughts and feelings were impacted by HS symptoms.		
1.3.1 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
1.3.2 impacting mood	*"It became a nightmare. I was suffering physically and emotionally" (Article 10)*	6, 9, 10, 14

1.3.2.1 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
1.3.2.2 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
1.3.2.3 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
1.3.3 Lack of control	*“It lasted a fortnight; I was totally helpless.” (Article 6)*	1, 2, 3, 5, 6, 7, 10, 12, 14
1.3.4 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
2. Adjusting to life with HS		
2.1 Challenges People described several ways they found living with HS to be socially challenging.		
2.1.2 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
2.1.3 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
2.1.4 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
2.1.6 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
2.2 Facilitators People described what helped them cope with living with HS.		
2.2.1 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
2.2.1 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 2 different positive reactions.” (Article 8)*	1, 6, 7, 8
2.2.2 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,
2.2.3 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

Table 4 Descriptive themes on experiences of treatment for HS

DESCRIPTIVE THEMES ON LIVING WITH HS	**Illustrative quotes**	**Articles with data on sub-theme**
3. Healthcare and treatment experiences		
3.1 Access to information **People mostly described a lack of knowledge amongst healthcare professionals about HS. There were a few descriptions of knowledgeable healthcare practitioners who had helped them manage the condition.**		
3.1.1 Healthcare professional knowledge	"It's so rare to see a doctor who knows about HS" (Article 10)	5, 6, 7, 9, 10, 12
3.1.3 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
3.1.3 Limited access to services	"Getting in to see a dermatologist is like getting to see the president" (Article 10)	6, 9, 10, 14
3.2 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.**		
3.2.1 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
3.2.2 Distrust	"Distrust of doctors is rampant … People say I don't trust the medical field" (Article 10)	10
3.2.3 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
3.2.4 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
3.3 Treatment experiences **People described the experiences of seeking treatment, learning to manage the condition, concerns about treatment and the burdens of treatment.**		
3.3.1 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
3.3.2 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

3.3.3 Self-management involved – 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
3.3.4 Burden on time	“Time spent on treatment” (Article 12)	7, 12, 14
3.3.5 Concern about side effects or symptoms from treatments	“Concern about medication and side effects” (Article 9)	7, 9, 12
3.3.6 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