



REVIEW

Burden of Hidradenitis Suppurativa: A Systematic Literature Review of Patient Reported Outcomes

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ABSTRACT

Introduction: Hidradenitis suppurativa (HS) has a profound negative impact on patients' health-related quality of life (HRQoL). Here we summarize the evidence on HRQoL and Patient Reported Outcomes (PROs) in patients with HS in real-world settings by conducting a systematic literature review (SLR) of observational studies.

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Methods: Data sources included MEDLINE, Embase & PsycINFO between January 1, 2010 and August 29, 2021, and conference proceedings between 2019 and 2021. Identified abstracts were reviewed and screened independently by two reviewers. Eligibility criteria included patients with HS of any severity, sample size ≥ 100 , reporting PROs including HRQoL measures. Included studies were critically appraised.

Results: Fifty-eight observational studies matched inclusion criteria. Dermatology Life Quality Index (DLQI) was the most commonly utilized instrument: 57% of included studies reported mean baseline DLQI scores, ranging between 8.4 and 16.9, indicating a very large impact on the patients' HRQoL. Higher scores were reported with increasing disease severity and among female patients. Pain was assessed mostly by an 11-point (0–10) numeric rating scale (NRS) with a mean baseline score ranging from 3.6 to 7.7 indicating moderate to high pain levels. There was a negative impact of HS on patients' psychological well-being, based on PRO scores related to depression and anxiety. A high proportion of sexual dysfunction was reported, with a larger impact on women than men. Work productivity and leisure activity were consistently found to be impaired in patients with HS.

Conclusions: All included studies reported a negative impact of HS on patients' lives. A diverse set of disease- and non-disease-specific

PRO instruments were utilized highlighting the need for more consistent use of HS-specific validated PRO instruments to assess the impact of HS on the different aspects of patients' HRQoL to allow for data to be more meaningfully interpreted and compared in real-world settings. Patients with HS need better disease management approaches that address the observed low quality of life.

PLAIN LANGUAGE SUMMARY

Hidradenitis suppurativa (HS) is a skin disease, which mainly involves the hair follicles, and may greatly affect the health of those with the illness. HS often causes painful or itchy bumps or swelling of the skin, especially in the intimate areas. These occasionally drain and have an odor. When they heal, sometimes they leave dark spots or scars. People with HS can feel depressed, anxious, or embarrassed, among other things. In this study, we looked at how existing studies measured the impact of HS on the physical, mental, and social quality of people's lives. When searching the Internet, we found 58 publications on studies around this topic. Across all of the studies, HS had a large negative effect on patients' quality of life. We found that the groups of people which were impacted more by HS had worse cases of the disease. Patients with more severe HS felt higher levels of pain. Women were also affected more than men. Many studies showed that patients with HS often felt depressed and anxious. Three studies showed that HS greatly affected women's sexual health. Many patients said that HS made it hard to work and do things for fun. More and better treatments are needed since HS can have such a big impact on people's lives.

Keywords: Hidradenitis suppurativa; Quality of life; Impact; Real-world evidence

Key Summary Points

A systematic literature review was conducted to summarize the evidence on health-related quality of life (HRQoL) and patient reported outcomes (PROs) observed in patients with hidradenitis suppurativa (HS) in real-world settings.

All included studies reported a negative impact of HS on patients' lives including high levels of pain, anxiety, depression, sexual dysfunction, and impaired work productivity.

Dermatology Life Quality Index (DLQI) was the most utilized instrument, and the mean baseline scores reflected a very large impact on the patients' HRQoL.

A diverse set of PRO instruments were utilized by the included studies, highlighting the need for more consistent use of HS-specific validated PRO instruments to assess the impact of HS on the different aspects of patients' HRQoL.

INTRODUCTION

Hidradenitis suppurativa (HS) is a chronic inflammatory skin disease that manifests as painful nodules, abscesses, draining tunnels, and scarring most commonly in axillary, inguinal, gluteal, and perianal sites [1]. HS can have a profound negative impact on patients' health-related quality of life (HRQoL), mainly due to the high disease burden resulting from symptoms, delays in diagnosis limited access to appropriate disease management, and disease-related comorbidity profile [2–5].

Dermatologists have highlighted in the past two decades the negative impact of this debilitating disease, and even reported that HS is one of the most distressing dermatological diseases and may cause worse impairment in QoL compared to other skin diseases [6].

A recent systematic literature review (SLR) has included 17 cross-sectional studies that assessed specifically pain, pruritus, and malodor on the quality of life of patients with HS [7]. This SLR has reviewed the comprehensive impact of HS on the different aspects of the HRQoL including the physical, psychological, sexual, and work-related aspects. Accordingly, we aimed to summarize all the domains of the HRQoL that are impaired in patients with HS and to assess the substantial evidence on the impacts characterizing symptom burden and quality of life impact in patients with HS in real-world settings by conducting an SLR of observational studies. The secondary objective was to assess the impact of HS on the physical, psychological, and sexual functioning of patients with HS by disease severity, gender, age groups, prior biologic use, country, and ethnicity.

METHODS

We conducted an SLR following the guidance issued by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement and the Cochrane collaboration. Data sources for retrieval of relevant publications encompassed three electronic databases (MEDLINE and MEDLINE In-process, e-pubs ahead of print, Embase & PsycINFO (OVID SP®) (Supplementary Table S1) as well as 2019–2021 conference proceedings from American Academy of Dermatology Association, International Society for Pharmacoeconomics and Outcomes Research (ISPOR), European Hidradenitis Suppurativa Foundation (EHSF), World Congress of dermatology (WCD), European Academy of Dermatology and Venereology (EADV) conference, and British Association of Dermatologists (BAD). A search strategy that combines free-text and controlled vocabulary terms was conducted in August 2021. Hand searching of references of the five most recent and relevant literature reviews was also conducted [7–11].

Article inclusion criteria were pre-specified and by population, intervention, comparators, outcomes, and study design (PICOS), and included the following: observational studies

addressing any HRQoL and/or patient reported outcomes (PRO) of patients with HS (any HS severity and any age), published between January 2010 until August 2021, and including at least 100 patients with HS. We chose 2010 as a starting point since HS research started to greatly accelerate around that time and HS-validated instruments were starting to be developed. We restricted our search to English language publications with no restriction on the types of treatment received or country of the study. Identified abstracts were reviewed independently by two reviewers followed by screening of eligible full texts. Conflicts between the two reviewers were resolved by discussion, followed by review of a third senior reviewer. A PRISMA flow diagram indicating the numbers of studies included and excluded at each stage of the review was prepared (Fig. 1). Included studies were critically appraised using Newcastle–Ottawa scale. A comprehensive extraction for relevant data was conducted for each included study comprising details on study characteristics, patient characteristics at baseline (time of the cross-sectional survey or case identification or start of follow-up), HRQoL, and PRO measures used in the studies and results of the same stratified by disease severity, gender, age groups, use of prior biologics, country, and ethnicity where available.

Ethics approval was not required for this study, as this article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

This SLR was not registered.

RESULTS

A total of 1449 records were identified, of which 875 were screened after eliminating duplicates across databases at the first level of title and abstract screening. There were 112 full text publications reviewed to assess eligibility based on predefined inclusion criteria (Fig. 1). There were 58 observational studies comprising 48 articles and 10 conference abstracts that were included. Among these studies, there were 41

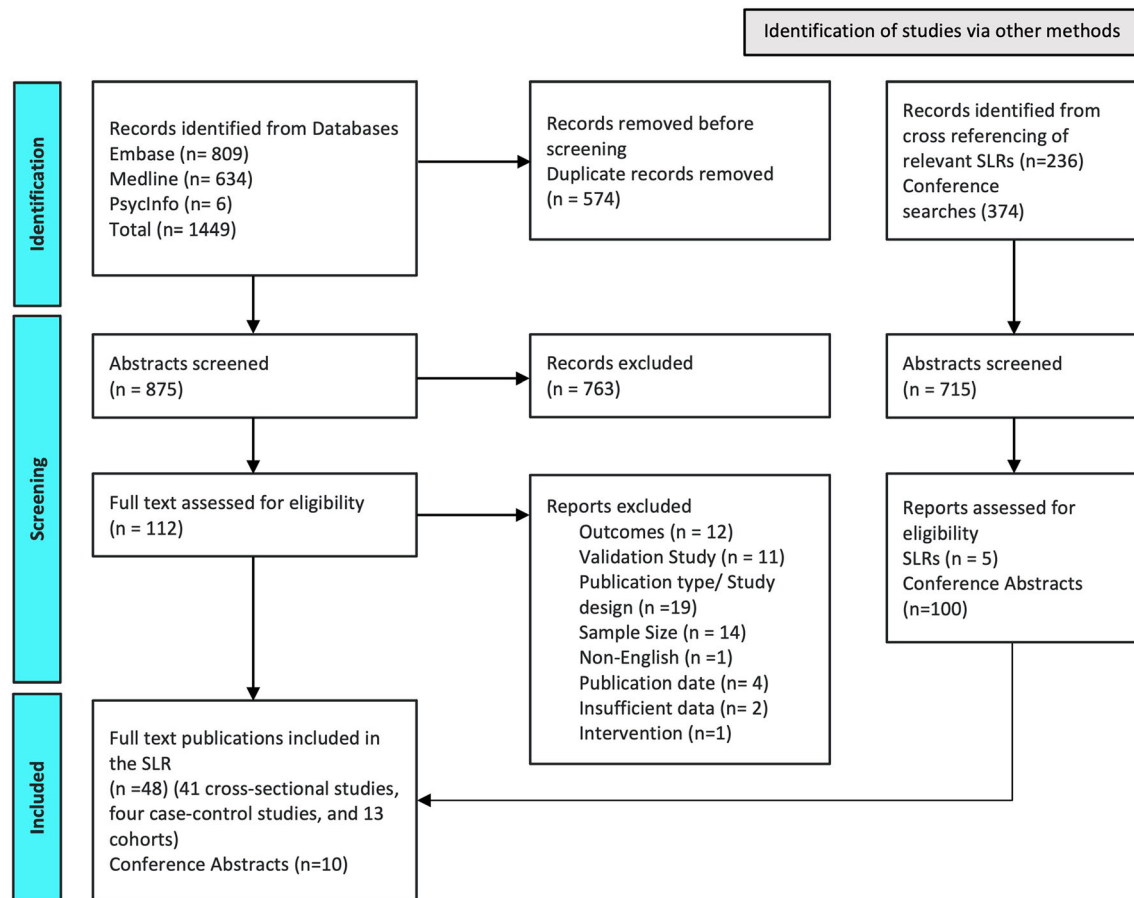


Fig. 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram for the inclusion of studies. *SLR* systematic literature review

cross-sectional studies, four case-control studies, and 13 cohort studies [5, 12–68].

Of the included studies (Supplementary Table S2), eight were conducted in each of Denmark and the USA, seven in each of Spain and Italy, four in each of Germany and the Netherlands, two in each of the UK, Poland and Greece, and one study in each of Canada, France, Norway, and Brazil. Six were multicenter studies.

Most studies had a cross-sectional design with a primary objective of studying patient characteristics and the disease impact on HRQoL. Few studies ($n = 4$) assessed effectiveness of surgical and medical interventions for patients with HS using different PRO instruments [20, 21, 24, 38].

The majority (85%) of the included studies were deemed of high quality with respect to reliability of data sources, accuracy of HS diagnosis and staging, and assessment of outcomes (Supplementary Figs. S1–S3).

Supplementary material provides an overview of the diverse set of PRO instruments that were utilized to assess different aspects of HRQoL (Supplementary Table S2). Validated instruments include Dermatology Life Quality Index (DLQI), HIDRADisk, EQ5D, SF-36, HS Symptom Assessment (HSSA) and HS Impact Assessment (HSIA), visual analogue scale (VAS), and numeric rating scale (NRS). Non-validated instruments include the following: Skindex 16, 17, 29, Body Image Quality of Life Inventory (BIQLI), Patient's Global Assessment of HS, HS quality of life, NRS for HS impact on sex life,

SF12, Patient's global assessment (PGA), 4-item Itch Questionnaire, 5-D Itch scale, Bodily Pain Scale of SF-36, and McGill Pain Questionnaire.

Patients Characteristics

Sample sizes ranged from 100 (a priori set as an inclusion criterion) to 1795 (Supplementary Table S3). Fourteen publications included both adults and adolescents. Mean age among adults ranged from 20 to 48.4 (male patients) and 20–43.5 (female patients) years. The average proportion of female patients was 70%. Disease severity was reported in 38% of included studies, and the proportion of moderate-to-severe HS ranged from 26% to 100%.

Overall HRQoL

Instruments developed for dermatological diseases to assess HRQoL such as the DLQI were utilized by 33 included studies (57%). Figure 2a displays the overall DLQI mean scores at baseline. The DLQI total scores were reported to be above 10 at baseline for all the included studies except one, and ranged from 8.4 (standard deviation [SD] 7.5) [40] to 16.9 (SD not reported) [21]. For patients treated with adalimumab, authors reported DLQI median to be 20 (IQR 12–25) [34]. These scores indicated a very large impact of HS on the HRQoL. Supplementary Table S4 displays the overall HRQoL scores derived from validated PRO instruments (including DLQI, HIDRADisk, EQ5D, SF-36, HSSA, and HSIA).

HRQoL Estimates for Subgroups of Interest

Figure 2b displays HRQoL scores provided by the six studies that have displayed data for patients stratified by Hurley staging (I, II, III). Mean baseline scores of DLQI, HIDRADisk, HSSA, and HSIA generally increased with increasing HS severity, indicating worse HRQoL particularly in patients with moderate and severe HS (Supplementary Table S5).

DLQI scores were numerically higher among female patients in four out of the five studies comparing gender groups (Fig. 2c). The

HIDRADisk questionnaire (specifically developed for HS) was utilized by one cohort study in Italy, in which the authors reported a statistically significant difference between female and male patients regarding the mean baseline HIDRADisk scores, indicating a poorer HRQoL in women compared to men with HS (Supplementary Table S6).

Pain in Patients with HS

Pain, the most debilitating symptom of HS, and the highest ranked item in the HiSTORIC core outcome set [69], was assessed as a separate component by 25 (43%) of the included studies. Instruments used included NRS and VAS which were utilized by 13 (22.5%) and 10 (17%) studies, respectively. NRS-Pain is an 11-point scale ranging from 0 “no skin pain” to 10 “skin pain as bad as you can imagine”. VAS has the same range as NRS, 0 corresponding to “unaffected by” and 10 corresponding to “worst imaginable pain”. Baseline NRS-Pain mean scores ranged from 3.6 (SD 3.2) to a maximum of 7.7 (SD 2.1) (Fig. 3a). The minimum baseline VAS-Pain mean score reported by the included studies was 3.9 (SD 3.2) in a survey in Denmark [43]. The maximum baseline mean VAS score of 7.3 (SD 2.4) was reported in an HS cohort admitted to the department of dermatology and venereology in Wroclaw Medical University, Poland [25]. The highest median score was reported to be 8, with a range of 6–9 for patients treated with adalimumab [34] (Fig. 3b) (Supplementary Table S7).

There seemed to be higher pain mean scores for female patients compared to male patients (mean VAS scores 4.9–7.8 vs 3.9–7.4) [22, 57] and higher pain scores for severe HS compared to moderate and mild HS as assessed by Hurley staging [20, 24, 45] (Supplementary Table S8).

Other instruments have also been used to assess the pain in patients with HS in a very limited number of studies. These instruments included the following: Bodily Pain Scale of SF-36, joint pain VAS, McGill Pain Questionnaire, NRS boil-related pain, Worst Pain Numeric Rating Scale (WPNRS).

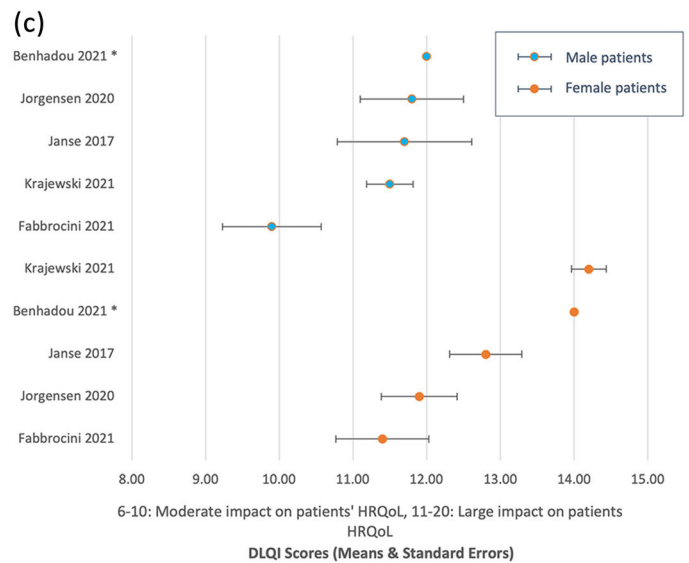
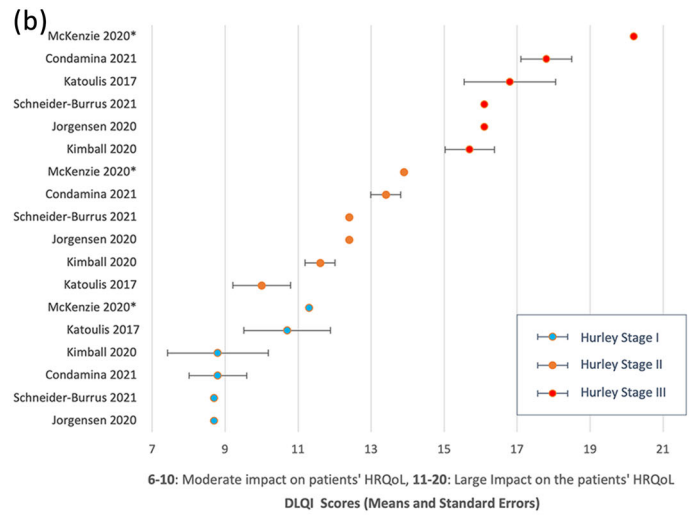
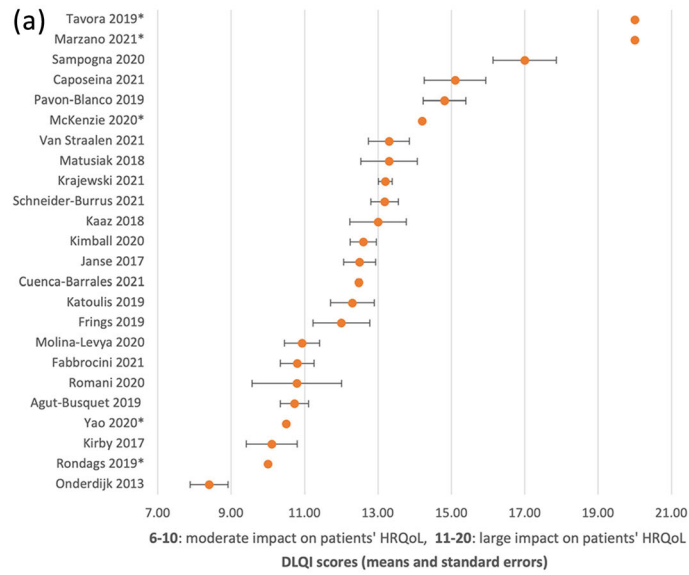


Fig. 2 **a** Overall DLQI mean scores at baseline: *Studies provided median and IQR. **b** DLQI mean scores at baseline stratified by severity of HS: *Study provided median and IQR; DLQI scores for the three Hurley stages were provided by six studies. —●— Hurley stage I, —●— Hurley stage II, —●— Hurley stage III. **c** DLQI mean scores at baseline stratified by sex: *Study provided median and IQR; Data provided by five studies —●— female patients, —●— male patients. *DLQI* Dermatology Life Quality Index, *IQR* interquartile range, *HS* hidradenitis suppurativa

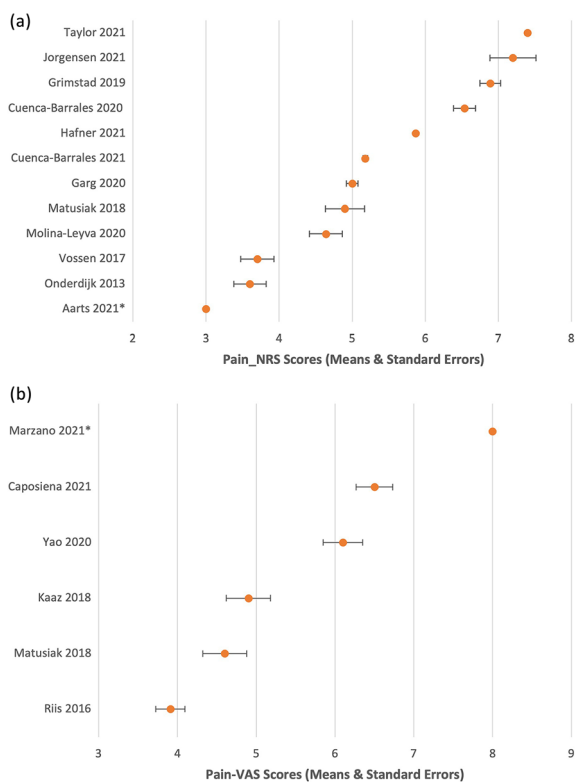


Fig. 3 **a** Pain NRS mean scores at baseline for patients with HS. **b** Pain VAS mean scores at baseline for patients with HS: *Studies provided median and IQR. *NRS* numeric rating scale, *HS* hidradenitis suppurativa, *VAS* visual analogue scale, *IQR* interquartile range, *HRQoL* health-related quality of life

Pruritus in Patients with HS

Pruritus was assessed in 10 (17%) of the included studies (Supplementary Table S9). For NRS-

Pruritus, values could range from 0 (no symptoms) to 10 (maximum intensity) [65]. With regard to VAS, the patients were asked to report and put two marks on the 10-cm-long horizontal line, to denote the maximal (VASmax) and mean (VASmean) intensity of pruritus in the past 7 days [35]. Mean baseline scores of NRS-Pruritus (8 studies, 80%) ranged from 3.3 (SD 3.1) to 6.4 (SD 3.0), while mean baseline VAS-Pruritus (3 studies, 30%) ranged from 3.7 (SD 3.2) [43] to 4.1 (SD 2.9) [25]. Other than NRS and VAS, two other instruments have been utilized by two studies to assess itching in patients with HS, the 4-item Itch Questionnaire and the 5-D Itch Scale.

Pruritus was correlated with insomnia as well as the sexual impact of HS. Kaaz et al. [25] conducted a study in Poland to assess the influence of pruritus and pain on sleep quality in 108 patients with HS compared to 50 healthy controls that did not have an itchy/painful skin condition of any type. The authors reported that 61% (66/108) complained of itching during the course of their HS and found that pruritus and pain were correlated with insomnia and sleep quality in patients with HS. Three other publications by Cuenca-Barrales assessed pruritus as part of evaluating the sexual impact of HS on 386 Spanish patients and reported a mean baseline NRS of 6.4 ± 3.0 [65–67]. Pruritus was among the factors that were associated with sexual distress in patients with HS in the univariate analysis.

Psychological Impact of HS

The psychological impact of HS was assessed by 13 (22%) of the included studies (Supplementary Table S10). There was a negative impact of HS reported on the patients' psychological well-being, reflected in the mean baseline scores of PROs related to depression, anxiety, mental health, and overall well-being. Higher anxiety scores (worse anxiety levels) and lower mental health components of different instruments indicated that HS substantially affects the psychological well-being of patients living with HS.

Hospital Anxiety and Depression Scale (HADS) is a 14-item questionnaire used to assess

anxiety and depression levels; a score of 0–7 is considered normal, 8–10 experiencing some symptoms, and 11–21 a probable presence of anxiety/depression [70]. Reported mean HADS scores are summarized in Fig. 4. HADS depression scores reported by Kimball 2020 indicated that 11% of adult patients with HS had some symptoms and 19.3% had probable presence of depression [28]. For HS adolescent patients, 11.1% had HADS depression scores indicating the presence of some symptoms and 4.8% the probable presence of depression. Regarding HADS anxiety scores, 25.8% of adult patients with HS exhibited some symptoms and 31.7% reported probable presence of anxiety; for adolescents, 22.2% had scores indicating the presence of some symptoms and 19.0% the probable presence of anxiety [28].

Supplementary Table S11 displays mean baseline scores reflecting the psychological impact of HS stratified by severity of HS. HADS depression and anxiety scores generally

increased with increasing HS severity, as reported in a cross-sectional study by Kimball that included 529 adults and 65 adolescents from the multinational UNITE registry [28].

Other instruments that have been utilized less commonly by authors include the following: Brief version of fear of negative evaluation scale, feelings of stigmatization questionnaire, generalized anxiety disorder-2, Major Depression Inventory, NRS overall disease-related distress, Patient Health 9-Item Questionnaire, Patient’s Health Questionnaire-2, Positive and Negative Affect Schedule (PANAS), SF-12—Mental health composite scores (two items), and Visual Analogue Scale for stress.

Sexual Impact of HS

Three (5%) of the included studies assessed the impact of HS on the sexual life of the patients, all of which reported a major negative impact

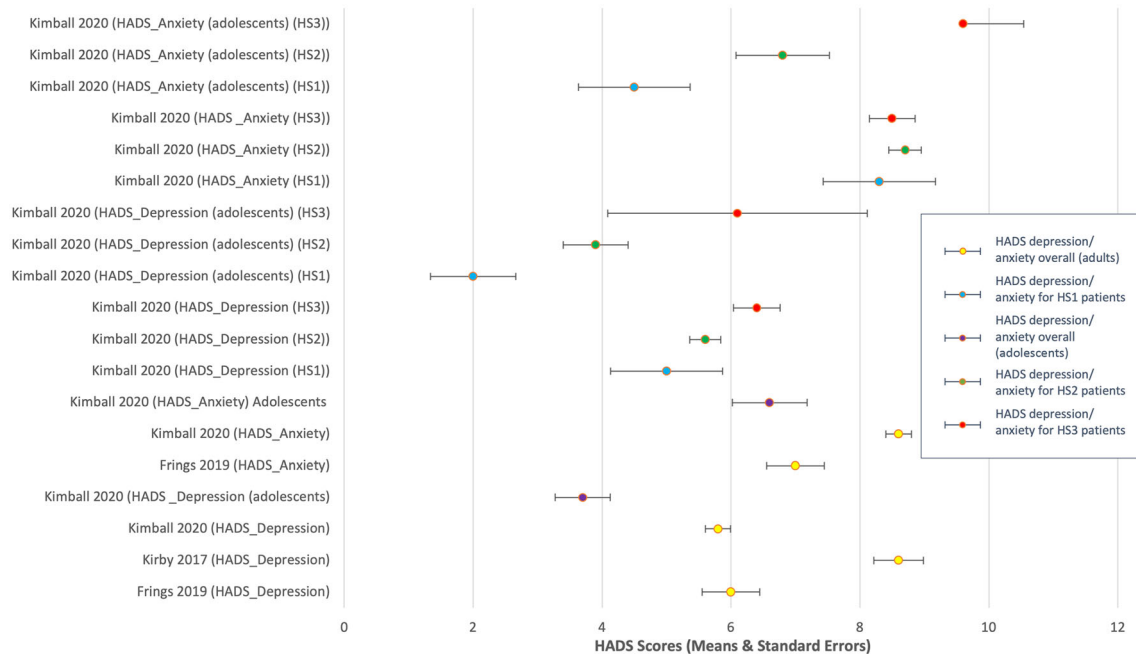


Fig. 4 HADS depression and anxiety mean scores at baseline for patients with HS: —●— HADS depression/anxiety overall (adults), —●— HADS depression/anxiety overall (adolescent patients), —●— HADS

depression/anxiety for HS1 patients, —●— HADS depression/anxiety for HS2 patients, —●— HADS depression/anxiety for HS3 patients. *HS* hidradenitis suppurativa, *HADS* Hospital Anxiety and Depression Scale

on sexual health of patients with HS compared to healthy individuals (Supplementary Table S12 displays mean scores for validated PRO measures). Sexual health and sexual impairment also had a larger impact on HRQoL in women than in men with HS [24, 65, 67]. A high proportion of sexual dysfunction in women (51%) and erectile dysfunction in men (60%) was reported in a cross-sectional study from Spain [65]. This study assessed risk factors of sexual dysfunction in patients with HS and the results suggested that sexual impairment in patients with HS is due, at least in part, to disease activity, symptoms, and active lesions. Related factors in women were intensity of pain and unpleasant odor, and education status, while in men they were the presence of active lesions in the genital area, the number of areas affected by active lesions, and increasing age. Janse 2017 reported that criteria of sexual dysfunction were met by 42% of the patients with HS in a multicenter cross-sectional study in the Netherlands. According to scores obtained in the 6-item Female Sexual Function Index (FSFI-6) questionnaire, 51% (95% CI 45–57%) of women suffered from sexual dysfunction (normal values > 19) [22].

Work Productivity and Activity Impairment in Patients with HS

Supplementary Table S13 displays the mean scores of PRO instruments reflecting the impact of HS on work and productivity. Four (7%) of the included studies assessed work productivity and activity impairment (WPAI). WPAI is expressed as a percentage of general (non-work) activity impairment due to HS ranging from 0 (no impairment) to 100 (total impairment).

According to Kimball 2020 [28], 60% of adults reported that they were employed, and the overall work impairment among employed adults in 12 countries was $48.9 \pm 29.5\%$. Additionally, some degree of activity impairment due to HS was reported by 74.7% (395/529) of all adults in this study. Absenteeism was reported by 27.9% (89/319) of employed adults, of which an average of $33.7 \pm 34.3\%$ of work time was missed because of HS. The overall mean

baseline work impairment ranged from 26.6% (single-center cross-sectional study from Denmark) [54] to 46.0% work productivity impairment and 53.3% activity impairment (cohort study of patients with HS treated with adalimumab) [21].

DISCUSSION

In this SLR, we have found that HRQoL mean scores from validated general and skin-disease-specific PRO instruments document the strong negative impact of HS on patients' lives. Pain was the most frequently assessed symptom using mainly NRS and VAS instruments, and the results show that patients with moderate to severe HS had a moderate to high degree of pain, with mean baseline NRS ranging from 3.6 (SD 3.2) to a maximum of 7.7 (SD 2.1). This finding is in line with a recent SLR and meta-analysis that reported that NRS was the scale most often used to assess pain with a pooled mean NRS of 4.0 (SD 1.0) based on random effect meta-analysis weighted by the study sample size [7]. Also, pain was the most burdensome symptom experienced by patients with HS [71]. Inadequate pain control was among the most frequently reported unmet needs from the perspective of patients with HS in a recent publication [72]. Pain reduction was also among the most important treatment attributes for patients with HS [73]. Somewhat unexpectedly, pruritus was the second most frequently assessed symptom with a high negative impact on patients with HS. It was also correlated with other aspects of life such as sleep and sexual health. Mental health was also shown to be affected in patients with HS with a lower degree of well-being and higher anxiety and depression scores compared to the general population or outpatients with other dermatological diseases. Other aspects of HRQoL were also found to be negatively affected, including sexual health, work productivity, and activity, which is affected by severity of HS.

We also collected data stratified by other variables of interest, but no consistent results were found in different studies except for Hurley staging, and the gender of the patients. An

interesting finding was that female patients showed statistically significant higher mean baseline scores using the HIDRADisk questionnaire, as well as DLQI, suggesting that the HRQoL of female patients might be more prone to be affected by HS than that of male patients. The consistent association between increase of severity of HS and mean scores of PROs measured by different instruments reflects the higher burden in patients with moderate and severe HS and the important need for better disease management in these patients. These findings are in concordance with a recent published literature review that found that female patients tend to experience a greater HRQoL impact than male patients and also highlighted an observed correlation between HRQoL and disease severity in patients with HS [11].

Another aspect of the HRQoL that has been assessed is work productivity and activity which was consistently found to be impaired in patients with HS across different disease severities. These results are in concordance with an observational study using claims data that found that HS is associated with high indirect burden, in terms of slower income growth, higher risk of leaving the workforce, and higher indirect costs, and indicated that patients with HS have unmet disease management needs [74]. Another recent publication concluded that productivity loss among patients with HS was the main cost component of the disease (53.3%) [75].

A large number of PRO instruments has been used in different studies to assess the impacts of HS on the different aspects of patients' HRQoL. DLQI, a skin disease-related QoL assessment tool, was the most frequently employed tool to assess HRQoL, as it was used by around 56% of the included studies, while other dermatology-related PRO instruments such as Skindex 17, 16, and 29 items were only used by four publications. The mean of baseline DLQI total score was reported to be above 10 at baseline for all the included studies (except one), ranging from 8.4 [40] to 16.9 [21], which is considered as a very large effect on the HRQoL [76]. These results are in concordance with the recent SLR and meta-analysis by Montero-Vilchez et al., in which DLQI was also found to be the most

frequently utilized instrument for assessing the HRQoL of patients with HS with a mean value of 10.7 (SD 2.16) [7].

There was limited use of specific instruments that were developed and/or validated specifically for patients with HS. HIDRADisk, for example, which is an innovative visual tool validated in 2019 to assess the burden of HS, was only used by one study, Fabroccini 2021, an Italian HS cohort study including 308 patients with a follow-up of 9 months [17]. Hidradenitis Suppurativa Quality of Life (HiSQoL) questionnaire was also specifically developed to encompass all the aspects of the HRQoL that are impacted by HS. On the basis of HiSQoL questionnaire, the lives of 27.2% of participants were moderately impacted while 43.3% were very much/extremely affected [5]. A more consistent use of HS-specific validated PRO instruments to assess the impact of HS on the different aspects of patients' HRQoL in future studies may lead to more generalizability and comparative value of results [77, 78]. This has been previously highlighted in published literature, in which authors have confirmed that outcome measure heterogeneity is a problem in HS research, as it would not allow comparison between results [71, 79–81]. On the basis of that, we have only highlighted results from validated PRO instruments.

Strengths of our SLR include the rigorous methodology, the comprehensiveness of the search strategy, and the high quality of most of the included studies which decreases the risk of bias, where authors depended on reliable sources for the recruitment of patients with HS that were diagnosed and assessed in dermatological clinics or specialized hospital departments. We have also encompassed estimates provided by studies that utilized validated instruments for the assessment of the HRQoL and other PROs of patients living with HS. Additionally, we included data from several subgroups of interest about the impact of HS on all the health aspects of patients with HS. The limitation is mainly our restricting analysis to studies published in English language and to those that included at least 100 patients with HS. However, this sample size was chosen to increase the generalizability of the results in this SLR. It is to be noted

that some of the included studies have an unexpectedly large sample size that is expected to increase the power of the results.

Montero-Vilchez et al. [7] recently published an SLR that aimed to summarize the evidence regarding the impact of HS signs and symptoms on QoL of patients. Those authors included 17 cross-sectional studies that assessed specifically pain, pruritus, and malodor in patients with HS. In contrast, the aim of the current SLR was to assess the evidence on HRQoL and PROs observed in patients with HS, and accordingly studies that assessed the psychological impact, or the sexual impact of HS, as well as the work productivity and activity impairment. Moreover, we have chosen, a priori, to include studies with a sample size of 100 and more, while Montero-Vilchez et al. [7] did not restrict the inclusion to a specific sample size, so there were not many included studies with fewer than 100 patients with HS.

CONCLUSIONS

All included studies reported a negative impact of HS on patients' lives based on the results of the PRO instruments reported to assess pain, pruritus, sexual functioning, anxiety, depression, psychological health, work productivity, and general HRQoL aspects. The negative impact is higher in patients with moderate and severe HS. These results suggest that there is a need for improvement of the management of patients with HS to better relieve patients from the burden of this chronic and debilitating skin disease. Different disease- and non-disease-specific PRO instruments have been utilized by the included studies which highlights the need for more consistent use of HS-specific validated PRO instruments to assess the impact of HS on the different aspects of patients' HRQoL for more consistent data generation in future research in a real-world setting.

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Data Availability. Data from non-interventional studies is outside of UCB's data sharing policy and is unavailable for sharing.

Declarations

Conflict of Interest. Alexa B. Kimball's institution received grants from Abbvie, Admirx, Anaptycs Bio, Aristeia, Bristol Myers Squibb, Eli Lilly, Incyte, Janssen, Moonlake, Novartis, Pfizer, Prometheus, UCB; Sonoma Bio;

Chemocentryx; she received consulting fees from Abbvie, Alumis, Bayer, Boehringer Ingelheim, Eli Lilly, FIDE, Janssen, Moonlake, Novartis, Pfizer, Priovant, Sonoma Bio, Sanofi, UCB; Target RWE, Ventyx; and serves on the board of directors of Almirall. Joslyn Kirby: Receives a stipend as Editor-in-Chief of the *British Journal of Dermatology* and an authorship honorarium from UpToDate; consultant for Boehringer Ingelheim, ChemoCentryx, Novartis, and UCB Pharma and has served on advisory boards for Inmed, Kymera Therapeutics, and Viela Bio, all in the field of hidradenitis suppurativa (HS); co-copyright holder of HiSQoL, Investigator Global Assessment and Patient Global Assessment instruments for HS; his department receives income from copyright of the Dermatology Life Quality Instrument (DLQI) and related instruments. John R. Ingram: receives a stipend as Editor-in-Chief of the *British Journal of Dermatology* and an authorship honorarium from UpToDate. He is a consultant for Abbvie, Boehringer Ingelheim, ChemoCentryx, Citryll, Novartis, UCB Pharma, and UNION Therapeutics and has served on advisory boards for Inmed, Kymera Therapeutics, and Viela Bio. He is co-copyright holder of HiSQoL, Investigator Global Assessment and Patient Global Assessment instruments for HS. His department receives income from copyright of the Dermatology Life Quality Instrument (DLQI) and related instruments. Tanja Tran: Employee of UCB Pharma. Ingrid Pansar, Valerie Ciaravino, Damon Willems: Employees and shareholders of UCB Pharma. Anne-Mary Lewis-Mikhael, Vanita Tongbram: Employees at Icon plc. Amit Garg: Advisor for AbbVie, Aclaris Therapeutics, Anaptys Bio, Aristea Therapeutics, Boehringer Ingelheim, Bristol Myers Squibb, Incyte, InflaRx, Inmed, Janssen, Novartis, Pfizer, UCB Pharma, Union Therapeutics, and Viela Biosciences, and receives honoraria; research grants from AbbVie, UCB Pharma, and National Psoriasis Foundation; co-copyright holder of the HS IGA and HiSQoL instruments.

Ethical Approval. Ethics approval was not required for this study, as this article is based on previously conducted studies and does not contain any new studies with human

participants or animals performed by any of the authors.

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