International Journal of Dermatology

Original Article

Inflammatory Diseases

Stigmatization and perceived health status in patients with hidradenitis suppurativa: an observational multicenter study in Europe

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Abstract

Introduction Hidradenitis suppurativa (HS) can severely affect the quality of life (QoL) and is linked to psychological distress, including anxiety, depression, and reduced self-esteem. Stigmatization due to physical appearance may significantly contribute to the psychological burden and impact on QoL for HS patients. This study investigates the association between stigmatization, depression, anxiety, and health- and disease-related variables among HS patients in Europe.

Patients and methods This observational cross-sectional multicenter study was conducted across 22 dermatological outpatient clinics in 17 European countries. Data collected included sociodemographic variables, general health variables, disease-related variables, perceived stigmatization (PSQ), and mental health (PHQ-2, GAD-2).

Results Of the 5487 dermatological patients, 142 (2.6%) were diagnosed with HS, and data from 135 patients (70.1% women, mean age 38.2 years) who completed the PSQ questionnaire were analyzed. Scores on the stigmatization measure indicated that significant stigmatization levels were present in the sample. Linear regression models revealed a significant relationship between stigmatization and both the duration of HS and the presence of itch. Similar findings were noted for the PSQ "confused/staring behavior" scale with depression. The PSQ "absence of friendly behavior" scale was inversely associated with general health status, whereas the "hostile behavior" scale was positively linked to depression.

Conclusion HS patients experience significant stigmatization linked to disease duration, itch, and depression. Comprehensive management, including screening for psychosocial co-morbidity, is essential, as is providing access to psychological interventions that support patients to both manage internal distress and the potential reactions of others.

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Keywords
itch; burden; hidradenitis suppurativa; stress; acne inversa; perceived health status; stigmatization.

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Conflict of interest: None.

Funding source: None.

doi: 10.1111/ijd.17569

Introduction

Hidradenitis suppurativa (HS) is a chronic inflammatory disease involving painful, deep abscesses and chronic, draining sinus tracts. The onset of HS is usually between puberty and the third decade of life,[1] and the spectrum of involvement ranges from mild to severe. Often, a delay in the diagnosis leads to a significant burden of disease.[2]

The severity of the disease and the high number of comorbidities can have a negative impact on patients' quality of life (QoL).[3–5] The negative impact is high even in patients with clinically mild HS.[3]

To date, HS has a poor response to treatment, and as a result, many patients experience disfiguring, pruritic, and painful lesions, malodor, scarring, and continuous suppuration, which negatively impact daily activities and lead to increased absenteeism from school or work.[6,7] Mental health disorders such as anxiety and depression are frequently associated with HS.[8–14] These conditions are also associated with a negative perception of body image and poorer self-esteem.[15]

Stigmatization, defined as the recognition of being devalued, discredited, or socially rejected due to a physical characteristic or feature, can lead to a significant emotional and social burden for patients, resulting from a distorted perception of themselves and how they are viewed by others.[16] Feelings of stigmatization may be present even in patients with mild forms of HS.[3,6,17]

The negative perception of body image may mirror the findings of increased anxiety and depression in patients with poorer self-esteem.

Variations in health-related and disease-specific factors, along with psychological factors such as stigmatization, can cause a burden that exceeds the actual severity of the disease.[18] Stigmatization has been shown to be significantly more frequent in patients with different dermatological conditions, including HS, in comparison to healthy skin controls.[19] The referenced study also revealed for the whole sample of included patients that certain sociodemographic factors such as a younger age, being male and single, body- and disease-related factors such as a higher BMI, a lower health status, the occurrence of itch, a higher severity of the skin disease and longer duration of the disease as well as certain psychological variables were significant predictors of stigmatization.[19] However, the study did not investigate predictors of stigmatization for patients with different dermatological conditions separately. The present study aimed to investigate the association between stigmatization, depression, anxiety, and health- and disease-related variables, specifically among patients with HS across Europe.

Patients and methods

Study design and participants

The data analyzed in this study are part of an observational cross-sectional multicenter study conducted in 17 European countries between September 2017 and December 2019, which aimed to investigate stigmatization and body image in patients with skin conditions.[19–21] Consecutive dermatological patients were recruited in 22 dermatological outpatient clinics until the required number of 250 respondents was reached. Inclusion criteria were age ≥18 years and being able to read and write in the local language. Participants were asked to sign a written informed consent. The study was approved by the Institutional Review Board of the Department of Medicine at the University of Giessen (protocol number 87/17) and each recruitment center and conducted in concordance with the Declaration of Helsinki.

In this study, we analyzed the subgroup of patients diagnosed with HS according to the ICD-10 classification.[21]

Collected data

Sociodemographic variables

Participants completed a questionnaire that included age, gender, educational level (no college, college, university), and marital status (single, with a partner).

General health-related variables

The EuroQol 5-D (EQ-5D)[22] visual analog scale (EQ-VAS) assessed the current health state. It consists of a vertical VAS from 100 (*The best health you can imagine*) to 0 (*The worst* *health you can imagine*). Its utility has been demonstrated in a large sample of dermatological European patients.[23] Body mass index (BMI, kg/m^2) was calculated using patients' self-reported height and weight. The dermatologist recorded physical comorbidities, particularly cardiovascular, respiratory, and rheumatological diseases and diabetes.

Disease-related variables

The dermatologist assessed disease severity as "mild", "moderate", or "severe." Localization (face, scalp, hands, torso, legs, and genitals), frequency of flare-ups, duration of the disease, and presence of itch in the last 24 hours were recorded.

Perceived stigmatization

Perceived stigmatization was assessed with the 21-item perceived stigmatization questionnaire (PSQ),[24] consisting of three subscales: "absence of friendly behavior", "confused/staring behavior", and "hostile behavior". Items were answered on a 5-point Likert scale, with higher scores reflecting higher levels of perceived stigmatization (total score range: 0–84). In a review on stigmatization assessment in visible skin conditions,[25] the PSQ was recommended based on its content validity and psychometric characteristics.

Depression and anxiety

The presence of depression and anxiety was screened using the 2-item Patient-Health-Questionnaire (PHQ-2)[26] and the 2-item General Anxiety Disorder (GAD-2, derived from GAD-7).[27] Items are answered on a four-point Likert scale ranging from 0 to 3 as follows: 0 (*never*), 1 (*several days*), 2 (*more than half of the days*), and 3 (*most days*). For each instrument, a score of 3 points is the preferred cut-off for identifying possible cases in which further diagnostic evaluation for generalized depression or anxiety disorder is warranted.

Statistical analysis

Categorical variables were described as numbers and percentages, and continuous variables as mean and standard deviations (SD). Tertiles of age distribution were calculated (<32, 32–43, and >43 years), as well as quartiles of EQ5D VAS score (>75, 60.1–75, 50–60, and <50), and tertiles of disease duration (<9, 9–18, and >18 years). The presence of comorbidities was defined as the presence of at least one comorbidity. Because of the skewness of PSQ scores distribution, differences in the PSQ distributions were compared using the Mann–Whitney *U* non-parametric test for categories and the Kruskal–Wallis test for more than two categories. Mean EQ5D VAS scores were compared in each PSQ item, dichotomized into 0 (*never/almost never*) and 1 (*sometimes, often, all the time*). Multivariate linear regression analysis was conducted with PSQ as the dependent variable to investigate its association with general health and psychological status while adjusting for possible confounders. Variables included in the model as independent variables were age, gender (male, female), EQ5D VAS score, PHQ-2, GAD-2, itch (yes/no), and stress (yes/no). All analyses were conducted using IBM SPSS Statistics for Windows, Version 26.0.

Results

Of all 5487 dermatological patients from the European sample, 142 (2.6%) were diagnosed with HS. For the present study, we analyzed data from 135 patients who had completed the PSQ questionnaire. Of them, 94 were women (70.1%), and the mean (SD) age was 38.2 (11.9) years. Mean PSQ scores for males and females, different education groups, and singles and persons living in a partnership are reported in Table 1. As already reported in the main paper on stigmatization[18] the mean (SD) PSQ total score was 19.3 (11.7), the PSQ "absence of friendly behavior" mean score was 11.2 (7.1), PSQ "confused/staring behavior" was 5.6 (6.4), and PSQ "hostile behavior" was 2.6 (3.2). No differences were observed regarding gender, age, education, and marital status, except the "hostile behavior" scale mean score, which was higher in men than women. PSQ scores were significantly associated with general health status (Table 2) measured by VAS, indicating a stronger sense of stigmatization in patients with lower health status. Also, a strong association was observed between high feelings of stigmatization and the presence of depression or anxiety. Higher PSQ total scale scores were observed in patients with rheumatological diseases. An association with at least one comorbidity was observed only for the "confused/staring behavior" scale. No associations were found for single comorbidities and in patients with visible flares compared to flares in nonvisible localizations (results not shown). Concerning disease-related variables (Table 3), the PSQ total score was associated with disease duration, the presence of flares on the face, and the presence of itch. The PSQ "confused/staring behavior" scale was also associated with clinical severity and itch evaluated by the physician, and the "hostile behavior" scale was associated with itch. General health status was consistently worse in patients who answered "sometimes/often/all the time" to the items of the PSQ indicating stigmatization and "never/almost never" to those indicating the absence of stigmatization. However, the difference was significant in only eight items (Figure 1). The items mainly belonged to the "absence of friendly behavior" scale.

The linear regression models (Table 4) showed a significant association between the PSQ total score and the two variables, the duration of the skin disease and the presence of itch. The same results were observed for the PSQ scale "confused/staring behavior" with "depression" as an additional predictor. The score on the PSQ scale, "absence of friendly behavior", was negatively associated with general health status, and on the PSQ scale, "hostile behavior", was positively associated with depression.

Table 1 Mean Perceived Stigmatization Questionnaire (PSQ) scores and sociodemographic variables in 135 patients with hidradenitis suppurativa

Variable	**Level**	***N*[a] (%)**	**PSQ Total score, mean (SD)**	***P*[b]**	**PSQ absence of friendly behavior, mean (SD)**	***P*[b]**	**PSQ confused/ staring behavior, mean (SD)**	***P*[b]**	**PSQ hostile behavior, mean (SD)**	***P*[b]**
Overall		135	19.3 (11.7)		11.2 (7.1)		5.6 (6.4)		2.6 (3.2)	
Gender	Male	40 (29.9)	22.1 (13.4)	0.127	12.0 (7.5)	0.274	6.7 (4.1)	0.227	3.5 (3.6)	**0.028**
	Female	94 (70.1)	18.0 (10.8)		10.7 (6.9)		5.2 (6.1)		2.2 (2.9)	
Age (years)	<32	43 (32.1)	19.4 (12.3)	0.709	9.9 (6.3)	0.277	6.6 (7.3)	0.469	3.1 (3.5)	0.150
	32–43	46 (34.3)	18.0 (10.4)		11.2 (7.4)		4.8 (5.7)		1.9 (2.6)	
	>43	45 (33.6)	20.4 (12.5)		12.4 (7.5)		5.4 (6.2)		2.8 (3.3)	
Education	No college	45 (34.9)	20.3 (12.1)	0.865	10.8 (7.3)	0.631	6.8 (6.8)	0.223	3.0 (3.3)	0.558
	College	52 (40.3)	19.3 (11.5)		11.4 (7.3)		5.4 (6.4)		2.4 (3.2)	
	University	32 (24.8)	19.2 (12.0)		11.9 (6.8)		4.7 (6.1)		2.6 (3.1)	
Marital status	Single	58 (43.9)	19.7 (11.3)	0.764	11.8 (7.2)	0.583	5.2 (5.8)	0.804	2.7 (3.3)	0.796
	With a partner	74 (56.1)	19.3 (12.2)		10.9 (7.2)		5.9 (6.9)		2.6 (3.1)	

Bold figures indicate $P < 0.05$.
PSQ, Perceived Stigmatization Questionnaire.
[a] Totals may vary due to missing figures.
[b] From Mann–Whitney *U* and Kruskal–Wallis non-parametric tests.

Discussion

HS is often described by patients as "boils". In an Occidental context, this is a culturally highly stigmatized concept, and yet only a few studies have analyzed stigmatization, emotional well-being, and health status in patients with HS. In our study, we demonstrated that patients with HS experienced significantly more stigmatization compared to controls.[18] To the best of our knowledge, there is only one study from Bouazzi et al.[28] that used the PSQ scale to measure stigmatization in HS. The authors described a sample of 43 HS patients from different continents and found a PSQ mean score of 15.4 (SD 12.6). In their study, feelings of stigmatization moderately correlated with other psychosocial variables such as depression, anxiety, QoL, and fatigue. In addition, similarly to the present study, they did not obtain a statistically positive relationship between stigmatization and age, relationship status, and level of education; in comparison, we have shown that pruritus and duration are related to the PSQ score. However, in our study, in contrast to the Bouazzi et al.[28] samples, the severity of the skin condition and being male were associated with more experience of confusing/staring behavior and hostile behavior, although this association was not confirmed in the linear regression analysis. On the other hand, this research has demonstrated that depression is a predicting factor of confusing/staring behavior, as well as hostile behavior (Graphical Abstract and Table 4).

Regarding the relationship between stigmatization and clinical severity, Singh *et al.*[17] reported that the majority of patients experienced feelings of being stigmatized, irrespective of the seriousness of their disease. Those who perceived a higher degree of stigmatization were also more inclined to exhibit reduced QoL, heightened levels of social anxiety, and depression.

We observed that only hostile behavior significantly differed between men (mean [SD] PSQ = 3.5 [3.6]) and women (mean [SD] PSQ = 2.2 [2.9]) ($P = 0.028$). Further research should investigate this in patients with HS.

Assessment of health-related QoL (HRQoL) has become one of the most important tools for evaluating both interventions and the impact of the disease on patients.[29] In our study, the mean score of perceived health status measured with the EQ-5D-VAS was 60.2 (SD 19.8), which is low compared to population norms. Matusiak et al.[6] reported lower EQ5D-VAS scores in their study of 54 patients (56.78 [SD:18.84]), whereas Bató et al.[30] in a sample of 200 patients, and Riis *et al.*[31] in 294 patients, found higher scores in the perception of health with the following respective scores: 62.2 (24.75) and 62.29 (22.68). In our study, 35.8% of the patients screened positive for depressive symptoms, but Ingram *et al.*[32] described a lower percentage (26%) in their study. Regarding anxiety symptoms, 45.9% of our patients screened positive, whereas Ooi *et al.*[18] reported significantly lower numbers in their sample of 45 patients with HS in Singapore, with only 15.5% positive for anxiety.

Finally, itch and pain are common symptoms in inflammatory dermatoses, significantly contributing to the feeling of stigmatization. Itch was self-reported in 65.2% of our patients compared to 15.4% of the control group ($n = 429$). Schut *et al.*[33] reported

Table 2 Mean Perceived Stigmatization Questionnaire (PSQ) and general health variables in 135 patients with hidradenitis suppurativa

Variable	**Level**	**N[a] (%)**	**PSQ total score, mean (SD)**	**P[a]**	**PSQ absence of friendly behavior, mean (SD)**	**P[a]**	**PSQ confused/ staring behavior, mean (SD)**	**P[a]**	**PSQ hostile behavior, mean (SD)**	**P[a]**
BMI	<25	24 (17.8)	15.3 (8.8)	0.206	9.0 (4.9)	0.391	4.5 (5.2)	0.757	1.7 (2.0)	0.277
	25–29.9	44 (32.6)	20.8 (11.8)		12.1 (6.9)		5.6 (7.1)		3.1 (3.2)	
	≥30	67 (49.6)	19.7 (12.4)		11.3 (7.96)		6.0 (6.4)		2.6 (3.4)	
VAS EQ5D (quartiles)	>75	34 (25.2)	14.4 (11.0)	**0.004**	9.2 (6.9)	**0.029**	3.2 (5.0)	**0.032**	2.0 (2.7)	**0.047**
	60.1–75	33 (24.4)	20.9 (11.3)		12.1 (7.2)		5.8 (5.7)		2.9 (3.9)	
	50–60	38 (28.1)	18.7 (11.6)		10.3 (6.0)		6.8 (7.4)		2.4 (3.4)	
	<50	30 (22.2)	23.7 (11.5)		13.5 (8.0)		6.5 (6.8)		3.7 (3.4)	
Comorbidities	No	81 (59.7)	17.4 (10.0)	0.087	10.8 (6.7)	0.468	4.5 (5.9)	**0.043**	2.1 (2.8)	0.098
	Yes	54 (40.3)	21.9 (13.5)		11.8 (7.9)		6.9 (6.8)		3.3 (3.6)	
Rheumatological diseases	No	119 (90.2)	18.5 (11.4)	**0.016**	10.9 (6.8)	0.082	5.1 (6.1)	0.135	2.5 (3.1)	0.294
	Yes	13 (9.8)	27.3 (12.0)		15.1 (9.4)		8.8 (7.9)		3.4 (3.7)	
PHQ-2 depression	0–2	87 (64.2)	16.4 (9.5)	**<0.001**	10.9 (6.9)	0.440	3.5 (4.1)	**<0.001**	2.0 (2.3)	**0.048**
	3–6	48 (35.8)	24.8 (13.4)		11.9 (7.4)		7.9 (5.5)		3.6 (4.1)	
GAD-2 anxiety	0–2	73 (54.1)	14.4 (9.4)	**<0.001**	9.9 (7.2)	**0.001**	3.0 (4.3)	**<0.001**	1.7 (2.1)	**0.001**
	3–6	62 (45.9)	25.0 (11.6)		12.7 (6.7)		8.7 (7.1)		3.7 (3.8)	

Bold figures indicate $P < 0.05$. Totals may vary due to missing figures.
GAD, general anxiety disorder; PHQ, patient health questionnaire; PSQ, perceived stigmatization questionnaire; VAS, visual analog scale.
[a] From Mann–Whitney *U* or Kruskal–Wallis non-parametric tests.

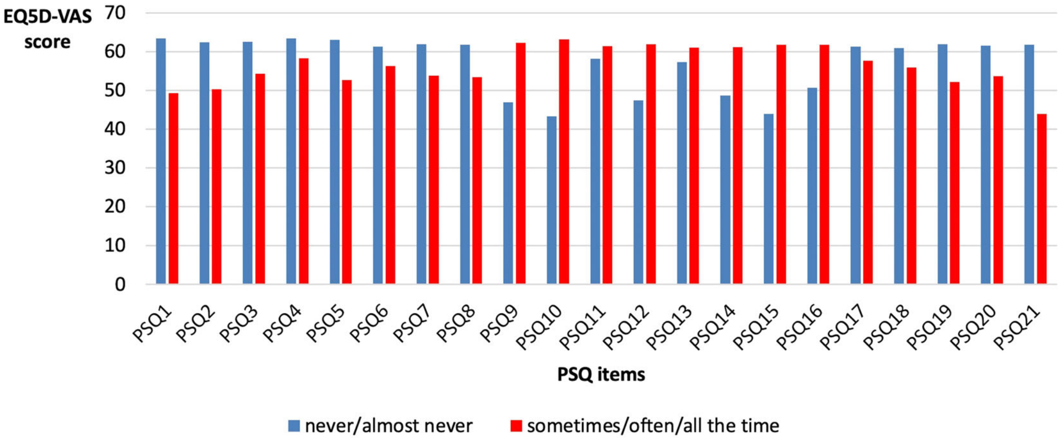
Table 3 Mean perceived stigmatization questionnaire (PSQ) and disease-related variables in 135 patients with hidradenitis suppurativa

Variable	**Level**	**N[a] (%)**	**PSQ total score, mean (SD)**	**P[a]**	**PSQ absence of friendly behavior, mean (SD)**	**P[a]**	**PSQ confused/ staring behavior, mean (SD)**	**P[a]**	**PSQ hostile behavior, mean (SD)**	**P[a]**
Clinical severity (physician)	Mild	35 (25.9)	15.8 (8.3)	0.114	10.8 (6.4)	0.715	2.8 (3.8)	**0.010**	2.2 (2.1)	0.920
	Moderate	67 (49.6)	19.1 (10.8)		10.2 (5.1)		6.3 (6.4)		2.6 (3.2)	
	Severe	33 (24.4)	23.3 (15.2)		13.5 (10.4)		6.9 (7.7)		3.2 (4.0)	
Duration (years)	<9	41 (32.0)	15.3 (9.8)	**0.027**	8.9 (5.3)	0.153	3.9 (4.4)	0.188	2.5 (3.2)	0.815
	9–18	44 (34.4)	20.4 (12.9)		11.8 (8.7)		5.9 (7.4)		2.6 (3.2)	
	>18	43 (33.6)	22.2 (11.8)		12.3 (6.6)		7.1 (6.7)		2.8 (3.2)	
Flares on face	No	109 (80.7)	18.0 (11.1)	**0.014**	10.7 (7.2)	**0.050**	4.8 (5.6)	0.073	2.4 (2.7)	0.627
	Yes	26 (19.3)	24.8 (12.8)		13.2 (6.5)		8.3 (8.2)		3.4 (4.5)	
Itch	No	47 (34.8)	14.9 (9.2)	**0.002**	10.4 (7.5)	0.153	2.8 (3.6)	**0.001**	1.6 (2.0)	**0.027**
	Yes	88 (65.2)	21.6 (12.3)		11.6 (6.9)		7.0 (7.1)		3.1 (3.5)	

Bold figures indicate $P < 0.05$. Totals may vary due to missing figures.
PSQ, Perceived Stigmatization Questionnaire.
[a] From Mann–Whitney *U* or Kruskal–Wallis non-parametric tests.

lower figures than ours: 45% in patients and 8% in controls. Similar results were obtained by Matusiak et al.,[34] with 34.9% of patients who reported itch. On the other hand, in a study carried out by MacKenzie et al.[35] on 145 patients, 82.1% reported itch.

Furthermore, an analysis of data from the NIH's All of Us Research Program showed that HS was associated with higher levels of stress and everyday discrimination compared to those without HS. Although the association between HS and discrimination in healthcare settings was not significant after adjusting



1. People avoid looking at me
2. People I don't know act surprised or startled when they see me
3. People don't know what to say to me
4. People feel sorry for me
5. People don't know how to act around me
6. People do "double takes" or turn around to look at me
7. People I don't know stare at me
8. People seem embarrassed by my looks
9. People are relaxed around me*
10. Strangers are polite to me*
11. People I don t know say "Hi" to me*
12. People are friendly with me
13. People I don't know smile at me in a friendly way*
14. People are kind to me*
15. People are nice to me*
16. People treat me with respect*
17. People call me names
18. People make fun of me
19. People bully me
20. People laugh at me
21. People pick on me
* Inverted scores

Figure 1 Mean EQ5D VAS score according to the single items of the Perceived Stigmatization Questionnaire (PSQ). Bold items indicate a significant difference ($P < 0.05$) between people answering never/almost never vs sometimes/often/all the time.

Table 4 Results of the linear regression models with PSQ total and scale scores as dependent variables

	Standardized regression coefficients (β)			
	PSQ total score	**PSQ absence of friendly behavior**	**PSQ confused/staring behavior**	**PSQ hostile behavior**
Gender (M = 1, F = 2)	−0.082	−0.082	−0.021	−0.105
EQ5-VAS health (cont.)	−0.095	−0.275*	0.112	0.041
Depression (PHQ-2) (cont.)	0.207	−0.156	0.401*	0.350*
Anxiety (GAD-2) (cont.)	0.184	0.085	0.204	0.069
Comorbidities (Y = 1/N = 0)	0.031	0.005	0.020	0.042
Clinical severity (physician) (cont.)	0.060	0.053	0.060	0.004
Duration (cont.)	0.171*	0.137	0.158*	0.059
Flare on face (Y = 1/N = 0)	0.140	0.128	0.070	0.067
Itch (Y = 1/N = 0)	0.159*	0.019	0.215**	0.138
R^2	0.384	0.154	0.439	0.244

All variables are adjusted on all the others. VAS health: high values = good subjective health; cont. = continuous variable.
F, female; GAD, general anxiety disorder; M, male; N, no; PHQ, patient health questionnaire; PSQ, perceived stigmatization questionnaire; Y, yes.
*$P < 0.05$;
**$P < 0.01$.

for demographics, the link to stress and everyday discrimination remained strong. These findings highlighted the importance of psychosocial well-being screening and support for individuals with HS.[36]

It is important to highlight how duration impacts patient stigmatization, as in other chronic dermatological diseases.[37,38]

A recent systematic review found that people with skin conditions experienced both physical symptoms and significant psychosocial distress, mainly due to stigmatization. This systematic literature review aimed to consolidate research on self-stigma in people with atopic dermatitis, psoriasis, vitiligo, alopecia areata, or HS and to identify targets for psychosocial interventions. A search of four databases yielded 27 studies that identified predictors of self-stigma, such as social stigma, coping strategies, and lack of social support. Most of the studies were cross-sectional, which limits causal interpretations. The findings suggest that psychosocial factors, particularly acceptance, may be effective targets for evidence-based interventions to improve the mental health of those affected.[39]

For this reason, it is essential to enhance effective screening protocols, coupled with pharmacological and non-pharmacological interventions, such as educational activities that provide the requested information, coping strategies, and social support that may help patients cope with the psychosocial burden of HS.[6,40,41]

In conclusion, the results of our study show that patients with HS experience significantly more stigmatization than controls and that feelings of stigmatization are associated with the duration of the skin disease and the presence of itch. Furthermore, depression is a predictor of confused/staring and hostile behavior, and general health status is inversely related to the absence of friendly behavior. Feeling stigmatized can hinder patients from adequately coping with the disease and negatively exacerbate emotions, which can lead to anxiety and depressive symptoms, as well as a poor perception of health status. This study demonstrates the importance of treating patients from a holistic standpoint that encompasses emotional, social, and functional symptom management, highlighting the importance of screening for symptoms of anxiety/depression and stigmatization. Experience of stigmatization may play an important role in mood comorbidities and perceived health status and should be taken into consideration in the management of our patients with HS.

IRB approval

The Institutional Review Board of the Department of Medicine at the University of Giessen, Germany (Protocol Number 87/17) and each ethics committee of all participating sites approved the study protocol.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Table S1. International Classification of Diseases, descriptions, and short category names.