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Internalized skin bias: Validation study to explore the impact of the internalization of social stigma on those with hidradenitis suppurativa

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Abstract

Background: Hidradenitis suppurativa (HS) is a chronic auto-inflammatory disease that is highly associated with adverse psychopathology and impaired body image. Previous studies show that patients with HS are also impacted by social stigma associated with their skin disease. Over time, these experiences can influence the way in which patients feel about themselves, leading to internalized skin bias (ISB).

Objectives: To evaluate the validity and reliability of the Internalized Skin Bias Questionnaire (ISBQ) in an HS population, and to determine the association of this instrument with markers of HS severity.

Methods: A cross-sectional survey with 72-hour retest was sent to adult patients with HS from March to November 2021. Reliability for the ISBQ was evaluated using Cronbach's alpha and the Concordance Correlation Coefficient (CCC). Construct validity was evaluated using Pearson Correlation Coefficients with similar measures.

Results: Internal consistency for the ISBQ instrument was 0.89 with a CCC of 0.88. The ISBQ had moderate correlation ($r = 0.63$) with the experienced skin stigma questionnaire as well as the BDI-II ($r = 0.66$) and the psychosocial subscale of the HiSQOL ($r = 0.65$). ISBQ scores differed significantly across different stages of disease severity (p=0.04). There was no significant difference between those with different durations of disease (p=0.47).

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Conclusions: This study shows that the ISBQ is a valid and reliable instrument that can be used to assess the psychosocial construct of ISB especially in a population of HS patients. Further, ISB places a prevalent negative impact on the psychopathology of patients with HS.

Keywords

hidradenitis suppurativa; psychodermatology; depression; internalized skin bias/ stigma; social stigma; survey validation

Introduction

Hidradenitis suppurativa (HS) is chronic dermatologic condition that is estimated to affect 0.1–2% of the population.[1,2] HS is an auto-inflammatory condition that causes papules, pustules, and nodules to manifest in the skin.[3] For those with more severe disease, patients can also develop abscesses and tunnels.[3] These lesions typically occur in the intertriginous regions of the body, can cause significant discomfort, have a malodorous discharge, and have a significant impact on the individual's health-related quality of life (HRQOL).[3–5] Recent studies have also shown that HS can have a significant impact on how individuals view themselves and endorse high levels of body image impairment.[6,7]

While for many with HS, the lesions themselves may reside in more "hidden" areas of the body, a number of studies have also highlighted that patients are impacted by the stigma that is associated with many skin diseases.[8] Historically speaking, skin diseases have been highly stigmatized[9–12] likely due to fears associated with the potential for contagion. Stigma theory was first introduced by sociologist Erving Goffman in the 1960's and posits that certain characteristics (such as manner of speech, attire, and grooming practices) cause certain individuals to stand out from normative society and as these individuals do not qualify for main stream societal acceptance, they are often marginalized or seen as social outcasts.[13]

This stigma associated with skin conditions and experienced in social exchanges can influence feelings of shame and guilt and could, over time, impact an individual's self-perception leading to feelings of internalized skin bias (ISB). ISB can therefore be defined as the adoption or redirection of negative social attitudes towards skin conditions towards how individuals perceive themselves. This concept of ISB was previously introduced by Alpsoy and colleagues in 2015 as internalized skin stigma (a synonymous construct) and applied to patients with psoriasis[14,15] and acne[16]. As both acne and psoriasis can present in areas of the body that are more visible to others (such as the face and limbs), both of these conditions have the ability to differentiate those with the disease from those without, and serve as the basis for stigmatization.[14–16]

Qualitative research methods have also highlighted the impact that stigma from external sources can have on patients with HS[17]; however, no studies have currently attempted to quantify the impact that the internalization of stigma (such as negative cognitions and emotions) may have on patients. Further, there are few instruments specifically designed to measure ISB. The majority measure experiential stigma or measure ISB specifically due to a certain dermatologic condition[11]. Thus, the purpose of this study is two-fold: 1) to evaluate the construct validity and reliability of a novel ISB instrument in an HS population and 2)

to determine the association of this instrument with markers of HS severity including Hurley staging and duration of disease.

Methods

Instrument Development and Pilot Testing.

The ISBQ is derived and adapted from a questionnaire that was developed by Durso and Latner in 2008 and called the Weight Bias Internalization Scale (WBIS).[18] The final WBIS instrument was reduced to 11 items with an internal consistency of 0.90 (Cronbach's Alpha) in an adult population with overweight or obesity.[18] The ISBQ was created by replacing the subject of the item in the WBIS from weight or overweight to skin condition and refined for general understanding. Each item was reviewed by a team including a clinical psychologist and a board-certified dermatologist. Items were also consistent with current literature regarding social biases related to skin diseases including impacts on mental health, self-hate, varying constructs of attractiveness, and impacts on social relationships.

The 11 ISBQ items were piloted in a post-bariatric sample (n=103) with prevalent dermatologic concerns at a single academic medical center[19] and demonstrated high internal consistency of 0.92; however, two items in particular had poor item-total correlation (Item 1: 0.25 and Item 9: 0.57). After removing these two items, internal consistency increased to 0.94 with all remaining items sustaining high item-total correlations. The ISBQ had a strong positive correlation (Pearson correlation coefficients) with the WBIS (0.68) and Dermatology Life Quality Index (DLQI; 0.78) and a moderate correlation with depression (0.50) and the anxious thoughts subscale (0.56). Test-retest reliability at 72 hours was high for the proposed instrument (0.88) using Person correlation coefficients. The final 9-item instrument was scored using a 7-point Likert scale from "strongly disagree" (0) to "strongly agree" (6). Item scores are summed with a total score range of 0 (no ISB) to 54 (extreme ISB). Prior to distribution in a population with HS, the instrument was reviewed again by a team including board-certified dermatologists, a clinical psychologist, patients with HS, and a clinical research and nursing team who staff an HS specialty clinic.

Procedures and Participants.

Participants were recruited from a group of patients diagnosed with HS who had volunteered for research studies at Penn State Health Milton S. Hershey Medical Center. Participants were also recruited virtually through ResearchMatch, and StudyFinder at Penn State Health, as well as network recruitment by allowing participants to share the link with others. Data were collected from April 1, 2021 through November 15, 2021. To be included in this research, patients needed to be: 1) 18 years of age or older, 2) able to consent, and 3) screen positive for HS through the use of 2-item screening instrument [2] OR have had active HS within the previous two years. A summary explanation of the research was provided at the beginning of the survey for patients to review. Participants affirmed their interest and if participants screened positive, they were then taken to the survey. The survey was built using REDCap, a secure online web application.[20] A retest portion of the survey was automatically sent to the patients after 72 hours in order to establish test-retest reliability for

a subset of the instruments. The Penn State Health Institutional Review Board reviewed all study procedures and this study was approved prior to distribution.

Measures.

Five instruments were included in this research: Internalized Skin Bias Questionnaire (ISBQ), Questionnaire on Experience with Skin Diseases – Short Form (QES-SF)[21], Hidradenitis Suppurativa Quality of Life (HiSQOL)[3], Beck Depression Inventory – II (BDI-II)[22], and the Burn's Anxiety Inventory (BAI)[23]. In addition to these five instruments, participants were asked to provide various demographic and health history information including: age, sex, race, ethnicity, level of education, employment status, duration of HS disease, self-staging of HS severity, smoking status, and history of mental health concerns. Self-staging of HS was conducted using a combination of photographic examples[24] along with descriptive qualifications of the various Hurley Stages.

The QES-SF is a 23-item validated instrument that measures experienced related to skin disease including feelings of stigmatization with higher scores indicative of increased negative perceptions related to dermatologic conditions.[21] The HiSQOL is a previously validated health-related quality of life (HRQOL) measure specifically designed for patients with HS.[3] Scores range from 0 (no impact on HRQOL) to 68 (severe impact on HRQOL). This instrument has three subscales including symptoms, psychosocial impact, and activity-adaptations. The BDI-II is a previously validated instrument to screen for depressive symptoms and is consistent with the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV) for the identification of pathology associated with depression.[22] The BAI is 33-item screening instrument for symptoms of anxiety and has three subscales including anxious feelings, anxious thoughts, and physical symptoms.[23] Higher scores for both the BDI-II and BAI are indicative of increased adverse psychopathology.

Statistical Analysis.

Descriptive statistics were used to characterize the population. All instrument scores were used in their linear outcome form and summary statistics (such as means, standard deviations [SD], and score ranges) were calculated. Instrument reliability was measured using Cronbach's alpha for internal consistency utilizing the ALPHA and NOMISS options in SAS PROC CORR. Test-retest reliability was calculated using concordance correlation coefficients (CCC) and 95% confidence limits (CL)[25] and was only calculated using those who indicated no change in disease status at the second screening. Convergent construct validity was determined by evaluating the associations between the ISBQ and QES-SF along with the affected self-esteem subscale, the BAI, BDI-II, and the psychosocial subscale of the HiSQOL using Pearson Correlation Coefficients (Pearson r) and 95% CL. Pearson r scores of 0.3–0.6 were considered fair, 0.61–0.80 were considered moderate, and 0.81–0.99 were considered very strong.[26] Differences in ISBQ scores among those with different Hurley stages and with different ordinal classes of duration of disease were compared using linear regression models. All statistical analyses were done using SAS Version 9.4 (SAS Institute Inc., Cary, NC).

Results

Participant characteristics are presented in Table 1. A total of 237 (82.87%) patients offered completed responses to this survey. An additional 49 (17.13%) participants elected not to participate (n=3, 1.05%), were ineligible based on the screening criteria (n=6, 2.10%), were duplicates (n=2, 0.70%), or had incomplete data (n=38, 13.29%), which was assumed as a withdrawal of consent. The majority of participants were female (n=216; 91.14%), non-Hispanic/Latino (n=210; 88.98%) and identified as White/Caucasian (n=183; 77.54%). Education was relatively evenly distributed with 118 (50.86%) participants obtaining a bachelor's degree or higher. The majority of patients self-identified as having Hurley Stage 2 (n=128; 54.24%) and 180 (76.27%) disclosed to having HS for 11 years or more. A third of the sample (n=89; 37.55%) identified as current smokers and 152 (66.96%) identified as having been diagnosed with a mental health condition such as depression, anxiety, bipolar disorder, etc. by a healthcare provider.

Summary statistics and reliability assessment of the ISBQ items are presented in Table 2. In total, 232 (97.89%) participants completed the ISBQ. The average instrument score was 36.05 with a standard deviation (SD) of 11.77. Internal consistency for the 9-item instrument was 0.89 with a CCC [95% CL] of 0.88 [0.83, 0.91]. Item-total correlations ranged from 0.31 to 0.75. Mean item scores ranged from 2.22 (SD: 2.03; Item 7) to 5.72 (SD: 0.70; Item 3).

Table 3 shows the Pearson r correlation statistics and 95% CL between the ISBQ and the various comparative psychosocial variables used in this study presented in descending order. The ISBQ had a moderate correlation (0.63 [0.54, 0.70]) with the experienced skin stigma questionnaire (QES-SF) as well as the BDI-II (0.66 [0.58, 0.73]), and the psychosocial subscale of the HiSQOL (0.65 [0.57, 0.72]). The ISBQ also had fair correlation with the anxious thoughts subscale of the BAI (0.58 [0.48, 0.66]), the affected self-esteem subscale of the QES-SF (0.54 [0.44, 0.63]), the total BAI score (0.56 [0.46, 0.65]), the anxious thoughts subscale of the BAI (0.54 [0.48, 0.66]), and the total HiSQOL score (0.53 [0.43, 0.62]).

Evaluating the ISBQ scores by markers of disease severity (Table 4) through the use of linear regression showed that patients with higher self-reported disease severity scores had significantly higher ISBQ scores (parameter estimate (β) = 2.50; Standard Error [SE] = 1.21; p=0.04). Mean ISBQ score were also significantly associated with the symptom's subscale (β = 0.83; SE = 0.16; p<0.0001) as well as the individual pain item (β = 2.67; SE = 0.60; p<0.0001) of the HiSQOL, which were used as additional markers of disease severity. Mean ISBQ show an increasing trend with increasing levels of self-reported disease severity with those with Hurley stage 3 endorsing the highest average scores of 37.28 (SD: 12.22). Scores for participants stratified by duration of disease were not significantly different (β = 0.57; SE = 0.78; p=0.47).

Discussion

This study showed the ISBQ is a valid and reliable tool to measure the degree to which patients with HS internalize negative social biases relating to HS. The ISBQ also demonstrated high reliability, including both internal consistency and test-retest reliability. Further, this instrument demonstrated strong construct validity when compared to a previously validated instrument used to measure experiential stigma related to skin diseases as well as other instruments aimed at evaluating adverse psychosocial outcomes. While one item in particular (Item 3) had lower item-total correlation than the other items (0.31), this item in particular had the highest mean score of all the items with no respondents indicating disagreement with this particular item, indicating that this item (“I wish I could drastically change my skin condition”) is strongly endorsed by individuals with HS. Consequently, the study team felt it necessary to retain this item for complete analysis.

This study also revealed that individuals with HS experience a high level of ISB with an average score of 36.05 (SD: 11.77), which is consistent with studies conducted in psoriasis and acne using different measures.[14,16] Participants’ scores are significantly higher ($p<0.0001$) when compared to the pilot test scores within a post-bariatric sample with the mean score being 24.23 (SD: 13.68). Scores suggest that patients with HS highly internalize social biases regarding skin health, which can have a substantive impact on the individual’s sense of self. Scores were statistically different among the different Hurley Stages, which was used as a marker of disease severity. As disease severity was based on self-report over clinical evaluation, some misclassification error may be present in this particular metric and could explain why the p-value did not fall below the level of significance. Surprisingly, ISBQ scores were not statistically different when stratified by the ordinal classes of duration of disease, suggesting that these notions may manifest early on and remain consistent throughout the disease process.

These findings are also consistent with research conducted in acne and psoriasis. In 2015, Alpsoy et al. introduced the Psoriasis Internalized Stigma Scale (PISS) and identified high levels of internalized stigma in a small psoriatic population in Turkey.[15] In this study on psoriatic patients and a larger multicenter study using the PISS, authors found that internalized stigma was associated with disease severity and impaired HRQOL and can be a contributing factor to adverse psychopathology associated with psoriasis.[14,15] The PISS was later applied to those with acne to form the Acne Internalized Stigma Scale (AISS). The study to test the AISS supported the previous findings to those in the psoriatic populations with patients endorsing high levels of internalized stigma and associated with negative HRQOL, severity of acne, and poor psychosocial health outcomes.[16]

Patients with HS have historically suffered from depressive and anxious symptoms along with the physical manifestations of HS.[27,28] This adverse psychopathology can have a significant impact on HRQOL[5,29], increasing the risk for suicidal ideation and suicide.[30] Previous studies have shown that patients with HS are 2.4 times as likely to commit suicide when compared to healthy controls.[30] Understanding the impact ISB has on patients with HS is a vital step in elucidating the mental health impact of this disease and can help

providers develop more targeted mental health interventions to mitigate the effect that HS has on the mental well-being of patients.

The ISBQ stands out from other stigma-related instruments as the ISBQ is not disease specific and therefore can be applied to various dermatologic conditions. Additionally, the ISBQ specifically measures the degree to which patients internalize, rather than experience negative social biases related towards skin diseases. The distinction between experienced (or social stigma) and internalized bias is extremely important in the context of psychological processes.[31] While many individuals may experience stigma directed towards them in interpersonal exchanges, the internalization of these sentiments may lead to greater psychopathology by exacerbating or engendering depressive and/or anxious feelings.[31] Thus, a more complete understanding of how constructs like ISB have on patients with HS can help guide clinicians to address better the mental well-being needs of this particular population. Further, patients showing signs consistent with ISB can be referred for adjuvant mental health treatment such as cognitive behavioral therapy.[32–36]

Limitations

Limitations to this research include a relatively small sample size for a validation study. Further, participants for this study were recruited from a single academic medical center as well as through network sampling on social media support platforms contributing to potential selection bias and may impact the generalizability of the findings to a larger population of patients with HS. Most notably, those with milder cases of HS were limited, rates of higher education were increased, rates of female and White patients were elevated, and rates of adverse psychopathology were increased as well. Lastly, disease severity was obtained through self-report using a self-staging questionnaire and may contribute to misclassification regarding disease severity.

Conclusions

This study suggests that the ISBQ may be a valid and reliable instrument to assess the psychosocial construct of ISB especially in a population of HS patients. While this is a small sample size, our data suggests ISB places a prevalent negative impact on the psychopathology of patients with HS, increases as disease severity increases. The lack of association between duration of disease and ISBQ scores underscores the pervasive nature that ISB can have in this particular population. Future studies should aim to establish evidence-based interventions to address this important construct in psychosocial health.

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Data Availability Statement:

Data not available due to ethical restrictions.

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Table 1.

Participant Characteristics (N=237)

Variable	Mean (SD); Range
Age	39.01 (11.17); [18,77]
BMI	36.57 (9.09); [16.30, 62.65]
	n(%)
Sex	
Male	20 (8.44)
Female	216 (91.14)
Decline to Answer	1 (0.42)
Ethnicity	
Hispanic/Latino	19 (8.05)
Non-Hispanic/Latino	210 (88.98)
Decline to Answer	7 (2.97)
Race	
Asian/ Pacific Islander	3 (1.27)
Black/African-American	29 (12.29)
Native American/Alaska Native	3 (1.27)
White/Caucasian	183 (77.54)
Two or More	10 (4.24)
Other	6 (2.54)
Decline to Answer	2 (0.85)
Education	
High School Diploma/GED or Less	70 (29.66)
Vocational/Trade School	44 (18.64)
Bachelor's Degree	74 (31.36)
Graduate Degree	44 (18.64)
Decline to Answer	4 (1.69)
Self -Stage	
Hurley Stage 1	28 (11.86)
Hurley Stage 2	128 (54.24)
Hurley Stage 3	80 (33.90)
Duration of Disease	
0–5 years	29 (12.29)
6–10 years	27 (11.44)
11–20 years	89 (37.71)
21+ years	91 (38.56)
Smoking Status	
Current Smoker	89 (37.55)
Former Smoker	60 (25.32)
Never Smoker	88 (37.13)
Mental Health History	

Variable	Mean (SD); Range
Never diagnosed or treated	75 (33.04)
Diagnosed but not treated	6 (2.73)
Diagnosed and previously treated	65 (28.63)
Diagnosed and currently treated	81 (35.68)

SD: Standard Deviation

BMI: Body Mass Index

GED: General Educational Development

Table 2.

Summary Statistics and Reliability for Internalized Skin Bias Questionnaire

Item Number	Item Description	N; Mean* (SD)	Standardized Variables	
			Correlation with Total	Alpha if removed
1	I am less attractive than most other people because of my skin condition.	232; 4.39 (1.67)	0.70	0.88
2	I feel anxious about my skin condition because of what people might think of me.	232; 4.79 (1.63)	0.71	0.88
3	I wish I could drastically change my skin condition.	232; 5.72 (0.70)	0.31	0.91
4	Whenever I think a lot about my skin condition, I feel depressed.	232; 4.67 (1.50)	0.75	0.87
5	I hate myself for my skin condition.	232; 2.97 (2.03)	0.73	0.88
6	My skin condition is a major way that I judge my value as a person.	232; 2.93 (2.04)	0.75	0.87
7	I don't feel that I deserve to have a really fulfilling social life as long as I have a skin condition.	232; 2.22 (2.03)	0.61	0.89
8	Because of my skin condition, I don't feel like my true self.	232; 4.18 (1.87)	0.66	0.88
9	Because of my skin condition, I don't understand how anyone attractive would want to date me.	232; 4.17 (1.98)	0.71	0.88
	Total	232; 36.05 (11.77)	**Cronbach's Alpha**	
			0.89	
	Test-Retest Reliability (n=122)		**Concordance Correlation Coefficient [95% CL]**	
			0.88 [0.83, 0.91]	

*Total score range is from 0 (lowest score) to 6 (highest score).

SD: Standard Deviation

CL: Confidence Limits

Table 3.

Construct Validity for Internalized Skin Bias Questionnaire

	Pearson *r* [95% CL]	**P-Value**
BDI-II	0.66 [0.58, 0.73]	P<0.0001
HiSQOL – Psychosocial	0.65 [0.57, 0.72]	P<0.0001
QES-SF	0.63 [0.54, 0.70]	P<0.0001
BAI – Anxious Thoughts	0.58 [0.48, 0.66]	P<0.0001
BAI	0.56 [0.46, 0.65]	P<0.0001
QES-SF – Affected Self-Esteem	0.54 [0.44, 0.63]	P<0.0001
BAI – Anxious Feelings	0.54 [0.48, 0.66]	P<0.0001
HiSQOL	0.53 [0.43, 0.62]	P<0.0001

CL: Confidence Limits

BDI-II: Beck’s Depression Inventory – II

HiSQOL: Hidradenitis Suppurativa Quality of Life

QES-SF: Questionnaire on Experience with Skin Diseases – Short Form

BAI: Burn’s Anxiety Inventory

Table 4.

Associations of Internalized Skin Bias and Markers of Disease Severity

Variable Level	N; Total Mean (SD)	Parameter Estimate (β)*	Standard Error*	P-Value*
Self- Reported Disease Severity				
Hurley 1	27; 30.85 (11.64)	2.50	1.21	0.04
Hurley 2	126; 36.46 (11.32)			
Hurley 3	78; 37.28 (12.22)			
HiSQOL – Pain Item				
Not At All	14; 29.07 (13.38)	2.67	0.60	<0.0001
Slightly	39; 35.74 (11.64)			
Moderately	61; 31.13 (11.43)			
Very Much	48; 37.40 (10.23)			
Extremely	70; 40.97 (10.63)			
HiSQOL – Symptoms Subscale				
Subscale Total	233; 8.60 (4.54)	0.83	0.16	<0.0001
Duration of Disease				
0–5 Years	28; 33.89 (12.70)	0.57	0.78	0.47
6–10 Years	26; 35.27 (13.01)			
11–20 Years	89; 36.98 (11.15)			
21+ Years	88; 35.91 (11.81)			

*Associations were evaluated using linear regression models

SD: Standard Deviation

β: Parameter Estimate

HiSQOL: Hidradenitis Suppurativa Quality of Life