To what extent do disease severity and illness perceptions explain depression, anxiety and quality of life in hidradenitis suppurativa?*

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Summary

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Background Hidradenitis suppurativa (HS) can have significant psychological consequences and affect quality of life (QoL). This has been associated with disease severity. However, it has not been established whether these effects are more strongly related to the severity of the disease, as rated by the clinician, or to the patient's perception of their condition.

Objectives To examine the relationships between disease severity and illness perceptions, and depression, anxiety and QoL in HS.

Methods This study was cross-sectional in design. In total, 211 patients with HS completed the Brief Illness Perception Questionnaire (BIPQ), the Patient's Health Questionnaire-2 (PHQ-2), the Generalized Anxiety Disorder-2 (GAD-2) and the Dermatology Life Quality Index (DLQI). HS severity was assessed by the clinician, using the Hurley staging system.

Results Patients with HS perceived their condition as chronic – having many symptoms, severe consequences and a negative emotional influence – and felt low personal control over their illness. Self-reports showed significant levels of depression, anxiety and impaired QoL, which were strongly associated with illness perceptions. Hierarchical regression analyses revealed that illness perceptions explained a much greater proportion of variance in depression, anxiety and QoL than the traditional explanatory variable, disease severity.

Conclusions HS can severely impair psychological well-being and QoL, which are more strongly associated with the person's beliefs about their illness than clinicians' severity assessments. Therefore, illness perceptions may be useful in the routine assessment of patients with HS and may provide a strong basis for interventions aimed at improving their psychological well-being and QoL.

What's already known about this topic?

- Hidradenitis suppurativa (HS) is known to be a highly distressing and debilitating skin condition that has a profound effect on quality of life (QoL), mood and anxiety.
- It has been assumed that these effects are directly related to disease severity.
- No previous studies have investigated patients' perceptions of their HS, and whether these are related to disease severity and/or their QoL and mood.

What does this study add?

- This study examines the illness perceptions of patients with HS, and the extent to which these are related to clinician-rated disease severity, mood and QoL.

> ## What are the clinical implications of this work?
>
> - The results suggest that illness perceptions are a stronger indicator of which patients with HS are most likely to be depressed, anxious or impaired in their QoL, relative to this skin disease's clinical measurement.
> - There is certainly scope for more routine assessment of patients' perceptions and for the development of interventions aimed at targeting negative illness beliefs with the aim of improving outcomes.

Hidradenitis suppurativa (HS), also called acne inversa, is a long-term, recurrent, debilitating inflammatory dermatological disease of the hair follicles. It is characterized by abscesses, sinus tracts and scarring, mainly affecting the apocrine-gland-bearing regions (axillae and anogenital and inframammary areas).[1,2] Persistent lesions may result in sinus tracts, usually accompanied by pain and malodorous suppuration.[1,2] Treatment varies according to disease severity, which is usually assessed using the Hurley[3] staging system.[1] HS is seen more among women. It tends to develop in patients in their 20s and its prevalence declines in people aged over 50 years.[4,5] Prevalence estimates of 1–2% have been reported in Europe.[5–7]

HS can have an extremely negative impact on patients' psychosocial and daily functioning and has been associated with anxiety, depression and impaired quality of life (QoL).[8–13] The occurrence of lesions in exposed areas and intimate sites, as well as odorous discharge that can stain clothing,[2,14] can result in difficulties with self-image and feelings such as stigma and shame for people with HS. Although studies of the impact of HS on psychological well-being and QoL are very limited, a higher prevalence of depression and poorer QoL have been found for HS compared with other dermatoses such as psoriasis, acne and chronic urticaria.[8–11,13] Depression and impaired QoL have also been linked to HS severity according to the Hurley staging system[8,9,13] and the Sartorius[15] scoring system,[13] although one study[9] found the association between depression and Hurley stage weak and borderline significant.

Increasing evidence among other chronic illnesses indicates that the individual's subjective beliefs about their condition are strongly related to health outcomes including depression, anxiety, QoL and recovery.[16–22] These beliefs, which are collectively referred to as illness perceptions, comprise the patient's own ideas about the nature, cause, controllability, time course and consequences of their condition.[23] Compared with clinical assessments of disease severity and demographics, illness perceptions have been found to be more strongly related to depression, anxiety and QoL in alopecia,[17,22] heart failure[18] and multiple sclerosis.[24] Thus, patients' illness perceptions may contribute to health outcomes more significantly than HS severity.

To date, no research has attempted to understand the nature of the illness perceptions of patients with HS and how they impact on health-related outcomes, such as depression, anxiety and QoL. Previous studies have focused mainly on describing clinical aspects of the disease and their relationships with health outcomes (depression, QoL and functioning)[8,9] and lifestyle behaviours (smoking and obesity).[5,25] Therefore, the aims of the present study were to explore firstly illness perceptions in patients with HS and secondly their relationships with health outcomes (depression, anxiety and QoL) independently of HS clinical severity. Thus, we hoped to investigate whether patient outcomes are more strongly related to clinicians' ratings of disease severity or to the patient's perception of their condition.

Patients and methods

This was an exploratory cross-sectional study. Data were collected between July 2014 and January 2015 at an HS tertiary clinic of a large teaching hospital in London. Given that the self-reported data were routinely collected as part of the Integrating Mental and Physical Healthcare: Research Training and Services (IMPARTS) initiative, which links electronic patient records, patients did not formally consent to participate but were informed that they could opt out of their data being used for research purposes. This conforms with the principles of the IMPARTS programme ethics approval (IMPARTS Research Database REC reference: 12/SC/0422).

Patients and procedure

All consecutive patients attending the HS tertiary service were invited to complete a series of self-reported questionnaires on a tablet device connected to the electronic patient record software via the hospital's Wi-Fi. Registered nurses trained in using the tablet informed patients about the data collection procedure, followed by an opt-out consent process. Patients visiting the clinic on more than one occasion throughout the data collection period were included during their first visit only. We excluded those who had visited the clinic between July 2014 and January 2015 who did not have HS (n = 10), thus an initial cohort of 221 participants was reduced to the final sample of 211.

Psychological and quality-of-life measures

Brief Illness Perception Questionnaire

The Brief Illness Perception Questionnaire (BIPQ)[26] is a validated, self-reported and reliable nine-item scale evaluating

cognitive and emotional representations of illness. *Consequences*, assesses the patient's perceived health outcomes of living with the illness; *timeline*, the perception of the duration of the disease; *personal control* and *treatment control*, the beliefs about the controllability of the disease; *identity*, the disease label and associated symptoms; *concern* and *emotional response*, emotional reactions to the illness; *understanding*, the patient's comprehensibility of their condition; and *causes*, the perceived aetiology of the disease (not included in this study). Each item is rated on a 10-point scale, where higher scores represent stronger endorsement with the illness perception. As recommended by the scale's authors,[27] each individual item value, not the overall score, was considered in this investigation.

Patient Health Questionnaire-2 and Generalized Anxiety Disorder-2

The Patient Health Questionnaire-2 (PHQ-2)[28] is a validated brief self-reported screening measure for assessing the frequency of depression and anhedonia within the last 2 weeks. It has been shown to be reliable in screening for depression in long-term conditions such as lung cancer.[29]

The Generalized Anxiety Disorder-2 scale (GAD-2)[30] is a reliable and standardized self-reported instrument for screening for generalized anxiety disorder in the last 2 weeks. It has been shown to be reliable in chronic conditions such as cardiovascular disease.[31]

For PHQ-2 and GAD-2, each item is scored on a four-point rating scale varying from 0 (not at all) to 3 (nearly every day), giving a score range of 0–6. Higher scores represent more severe symptoms, with a recommended optimal cut-off point of 3 reflecting core signs of depression disorder[28] or generalized anxiety disorder.[30] The Cronbach's alpha value for GAD-2 in the current sample was 0·89.

Dermatology Life Quality Index

The Dermatology Life Quality Index (DLQI)[32] is a 10-item validated and widely used self-reported measure to assess QoL in dermatological illnesses. The full score range is 0–30, with higher scores indicating more impaired QoL. Interpretations of cut-off points are 0–1, no effect on the patient's life; 2–5, small effect; 6–10, moderate effect; 11–20, very large effect and 21–30, extremely large effect.[33] Its internal consistency value in the current sample was 0·90.

Clinical and demographic information

The clinical stage of the disease and demographic information of the included patients were extracted from the electronic patient record. The Hurley staging system,[3] comprising three clinical stages – stage I (mild), stage II (moderate) and stage III (severe) – was used by clinicians to assess the severity of HS disease.

Statistical analyses

Statistical analyses were performed using SPSS for Windows version 22·0 (IBM, Armonk, NY, U.S.A.).[34] Post hoc power analysis on G*power 3·1[35] using the $n = 211$ sample size indicated 98% and 99% statistical power at a 0·05 alpha level (two-tailed) for detecting a medium and large effect size, respectively. The five-stage classification of Hurley's severity used for this sample was clustered into stages I, II and III following the original staging system and to allow for comparison of the results with the literature (Table 1).

There were no missing values, and preliminary analysis showed that nonparametric tests were appropriate for the data. Thus, Spearman's correlation coefficients were used to explore the associations between illness perceptions and age. Mann–Whitney U-tests were used to examine significant differences between illness perceptions across genders (data were recorded as 'gender'). We used Jonckheere–Terpstra tests to examine for ordered statistical differences in illness perceptions among the three disease severity groups, followed by post hoc pairwise comparisons. Hierarchical multiple regression models examined the contribution of illness perceptions to depression, anxiety and QoL, independently of HS clinical stage.

To control for the possible influences of confounders on the outcome variables, demographics (age and gender) and Hurley severity stage were entered into the regression analyses at steps 1 and 2, respectively. The BIPQ items were entered at step 3. The bias-corrected accelerated bootstrapping method (1000 samples) was applied to correct for heteroscedasticity and potential influential points and outliers. Statistical significance was defined as $P < 0.05$ given the exploratory nature of the present study.

Results

Baseline characteristics

The study included a total of 211 patients with HS aged 17–71 years (mean ± SD, 38·2 ± 11·8), with the majority being female (n = 126, 60%). The sociodemographic and clinical characteristics of the study cohort are displayed in Table 1.

Table 1 Sociodemographic and clinical characteristics of the study sample with hidradenitis suppurativa (HS)

Gender, n (%)	
Female	126 (60)
Male	85 (40)
Age (years), mean ± SD	38·2 ± 11·8
HS Hurley stage severity, n (%)	
Stage I[a]	45 (21)
Stage II[b]	64 (30)
Stage III	109 (52)
Current smoker, n/N (%)	86/210 (41)
Recreational drug user, n/N (%)	29/202 (14)

[a]Clustered from stages I and I/II. [b]Clustered from stages II and II/III.

Table 2 Distribution of Brief Illness Perception Questionnaire (BIPQ) scores and number and percentage of participants scoring above the scale midpoint

Dimension	Mean	SD	Median	Percentage of participants above midpoint (> 5)
Consequences	6·97	2·67	7	76
Timeline	8·49	2·49	10	84
Personal control	3·03	3·11	2	23
Treatment control	5·30	3·02	5	46
Identity	7·17	2·42	7	76
Concern	8·23	2·21	9	86
Understanding	7·03	2·62	7	72
Emotional response	7·26	2·92	8	78

Higher scores represent stronger endorsement of items.

Table 3 Spearman's rho correlation coefficients between illness perceptions and age, depression (PHQ-2), anxiety (GAD-2) and quality of life (DLQI)

	Age	PHQ-2	GAD-2	DLQI
Consequences	−0·18**	0·52**	0·48**	0·65**
Timeline	0·03	0·16*	0·07	0·11
Personal control	0·01	−0·17*	−0·19**	−0·21**
Treatment control	0·07	−0·20**	−0·16*	−0·20**
Identity	−0·09	0·39**	0·29**	0·59**
Concern	−0·15*	0·29**	0·23**	0·32**
Understanding	−0·12	0·02	−0·02	0·04
Emotional response	−0·26**	0·45**	0·52**	0·51**

PHQ, Patient's Health Questionnaire; GAD, Generalized Anxiety Disorder; DLQI, Dermatology Life Quality Index. *$P < 0.05$, **$P < 0.01$ (two-tailed).

Illness perceptions

Table 2 illustrates the patients' BIPQ scores and the number and percentage of patients scoring above the midpoint (> 5) for each illness perception. Most patients perceived HS as chronic and were worried about their illness. Most patients also felt that HS affects their life greatly (consequences) and that they had little control over their disease, experienced high levels of HS symptoms (identity) and had a strongly adverse emotional response to HS. They perceived their illness as fairly controllable through treatment and had a good understanding of HS.

Self-reported depression, anxiety and quality of life

Typically, participants' scores were below the threshold for clinically significant symptoms of depression (PHQ-2: median 2, mean $2·12 \pm 1·88$) and anxiety (GAD-2: median 2, mean $1·88 \pm 1·86$). However, around one-third (73 of 211, 35%) and around one-quarter (56 of 211, 27%) of participants scored equal to or above the threshold representing core symptoms of depression and anxiety, respectively.[28,30] Generally, participants reported very large effects of HS symptoms on QoL (DLQI: median 15, mean $14·81 \pm 8·45$). Furthermore, over one-third (81 of 211, 38%) recorded a DLQI score between 11 and 20, representing a very large impact of HS on QoL, while almost one-third (59 of 211, 28%) scored in the range 21–30, indicating an extremely large effect.[33]

Variations in illness perceptions by sociodemographics and hidradenitis suppurativa clinical severity

Spearman's correlations, Mann–Whitney U-tests and Kruskal–Wallis Dunn–Bonferroni tests were conducted to determine the differences in illness perceptions according to age, gender and disease severity (Tables 3, 4 and 5, respectively). Spearman's coefficients revealed that with increasing age, patients

attributed significantly fewer adverse consequences to HS ($r_s = −0·18$, $P = 0·008$) and had a significantly lower emotional response to the illness ($r_s = −0·26$, $P < 0·001$). Mann–Whitney U-tests showed that perceptions of timeline and treatment control were significantly higher for women (medians 10 and 6, respectively) than for men (medians 10 and 5, respectively): $U = 4374·5$, $z = −2·63$, $P = 0·009$, $r = −0·18$ and $U = 4474·5$, $z = −2·04$, $P = 0·041$, $r = −0·14$, respectively. Jonckheere–Terpstra tests demonstrated a significant trend of higher understanding of HS with higher disease severity ($J = 8748$, $z = 3·76$, $P < 0·001$). Pairwise comparisons revealed a significantly higher understanding for patients of Hurley stage III (median 8) vs. stage I (median 6); adjusted $P < 0·001$. There were no other significant differences between groups.

Relationships between illness perceptions and depression, anxiety and quality of life

Spearman's correlations were used to assess the relationships between illness perceptions and depression, anxiety and QoL, which are presented in Table 3. Overall, the results showed that higher levels of depression and anxiety and more impaired QoL were associated with more negative illness beliefs.

Three hierarchical multiple regressions further examined these associations (Tables S1–S3; see Supporting Information). The change in R^2 (ΔR^2) was tested for significance to examine whether illness perceptions account for additional variance in depression, anxiety and QoL over and above that accounted for by disease severity and demographics.

For depression, disease severity accounted for a significant amount of variance over and above demographic variables: $\Delta R^2 = 0·03$, $\Delta F(2, 206) = 3·75$, $P = 0·025$. Entry of illness beliefs into the model produced the greatest and most significant increase, explaining an additional 30% of the variance in depression scores: $\Delta R^2 = 0·30$, $\Delta F(8, 198) = 11·52$, $P < 0·001$. Inspection of the beta-coefficients revealed that

Table 4 Variations in illness perceptions by gender

Percentile	Male			Female			P-value	Effect size[b]
	25th	50th[a]	75th	25th	50th[a]	75th		
Consequences	6	7	10	6	7	9·25	0·84	−0·01
Timeline	6	10	10	9	10	10	0·009	−0·18
Personal control	0	3	5	0	2	5	0·60	−0·04
Treatment control	4	6	8	3	5	7	0·041	−0·14
Identity	6	7	10	6	7·50	9	0·70	−0·03
Concern	7	10	10	7	9	10	0·26	−0·08
Understanding	5	7	9·50	5	7	10	0·62	−0·03
Emotional response	5	8	10	6	8	10	0·59	−0·04

Higher scores signify stronger endorsement of the items. [a]Median. [b]Calculation for effect size estimate: $r = Z/\sqrt{N}$, where Z is the *z*-score of the U-test statistic and N is the sample size.[53]

Table 5 Variations in illness perceptions related to disease severity

Percentile[a]	Hurley stage I			Hurley stage II			Hurley stage III			Jonckheere–Terpstra	
	25th	50th	75th	25th	50th	75th	25th	50th	75th	J-value	P-value
Consequences	5	7	8	6	7	9	5	8	10	7626·5	0·18
Timeline	6	10	10	8	10	10	8	10	10	7413	0·31
Personal control	0	3	5·5	0	2	5	0	2·5	5	6973	0·96
Treatment control	4·5	5	7	2	5	7	3	6	8	7456·5	0·33
Identity	6	7	8	6	7	8·75	5	8	10	7599	0·20
Concern	7	9	10	7	8·5	10	7	10	10	7536	0·23
Understanding[b]	4·5	6	8	5	7	9	6	8	10	8748	< 0·001
Emotional response	6	8	10	6	8	10	5	8	10	6992	0·99

Higher illness perception scores signify stronger endorsement of the items. [a]The 50th percentile is the median. [b]Post hoc tests as follows. Standard test statistics: stage I vs. II, 1·78; I vs. III, 3·62; II vs. III, 2·09. Adjusted P-values: stage I vs. II, 0·11; I vs. III, < 0·001; II vs. III, 0·055.

perceptions of severe consequences [$\beta = 0.36$, $P = 0.001$, 95% confidence interval (CI) 0·13–0·39] and lower treatment control ($\beta = -0.20$, $P = 0.004$, 95% CI −0·21 to −0·04) were both significant contributors to depressive symptoms.

Interestingly, entry of severity stage did not explain additional variance in anxiety over and above demographic variables: $\Delta R^2 = 0.01$, $\Delta F(2, 206) = 1.22$, $P = 0.30$. The addition of illness perceptions into the model again contributed to the highest and most significant increment (27%) in the explanatory power: $\Delta R^2 = 0.27$, $\Delta F(8, 198) = 9.59$, $P < 0.001$. A higher emotional response ($\beta = 0.36$, $P = 0.001$, 95% CI 0·14–0·32), more negative consequences ($\beta = 0.33$, $P = 0.002$, 95% CI 0·11–0·34) and lower concern about HS ($\beta = -0.16$, $P = 0.027$, 95% CI −0·28 to −0·00) were significantly associated with increased anxiety.

For QoL, disease severity added a significant amount of variance beyond that accounted for by demographics: $\Delta R^2 = 0.08$, $\Delta F(2, 206) = 9.45$, $P < 0.001$. The addition of illness perceptions made the greatest significant contribution, explaining 47% of the variance in QoL scores above that already explained by the previous variables: $\Delta R^2 = 0.47$, $\Delta F(8, 198) = 26.78$, $P < 0.001$. Beliefs of greater adverse consequences ($\beta = 0.41$, $P = 0.001$, 95% CI 0·94–1·66), lower treatment control ($\beta = -0.13$, $P = 0.010$, 95% CI −0·65 to −0·12), a stronger identity ($\beta = 0.29$, $P = 0.001$, 95% CI 0·61–1·38) and a larger emotional response ($\beta = 0.18$, $P = 0.005$, 95% CI 0·14–0·91) showed significant effects in the variance explained for impaired QoL.

Discussion

To the best of our knowledge, this is the first study to identify an HS illness perceptions profile and to explore the relationships between illness perceptions and health outcomes in this patient group. The results are consistent with previous findings about the high levels of depression, anxiety and impaired QoL found in individuals with HS.[8–12] Interestingly, despite considerable variations in illness perceptions within the sample, our HS cohort showed higher perceptions of consequences, symptoms, concern and emotional response and lower personal and treatment control than patients with diabetes, asthma and myocardial infarction.[26,36,37] Overall, there was a lack of associations between a person's illness beliefs and their disease severity stage, which aligns with past

evidence in psoriasis[21] and systemic lupus erythematosus.[38] This is an important finding as it shows that illness perceptions are not a function of disease severity in HS, and that it is possible to examine the extent to which outcomes, such as depression and QoL, are more strongly related to clinician-dependent (Hurley stage) or patient-dependent (BIPQ) severity assessments. This highlights the potential discordance between patients' and doctors' evaluations of HS also found in other conditions[39,40] and discourages assumptions about how the patient sees their disease according to clinical measures.

In line with past research in alopecia[17,22] and other long-term conditions,[18,20–22,24] more negative illness beliefs were significantly intercorrelated with higher depression and anxiety and impaired QoL scores. Furthermore, after controlling for HS severity and demographics (age and gender) in multivariate analyses, illness perceptions explained more variance than disease severity and demographic factors together, for depression, anxiety and QoL. These findings are consistent with previous studies across a range of chronic conditions[17,18,20,24,41] and suggest a greater importance of individual's beliefs about their HS than disease severity and demographics in accounting for health outcomes. Contrarily to our results, Matusiak et al.[8] found that disease severity (measured by Hurley stage) was the most important factor influencing depression and QoL. Moreover, Kurek et al.[13] demonstrated that the higher the disease severity (assessed by the Sartorius scale), the higher the risk of depression. However, neither of the previous studies measured illness perceptions.

The most consistent significant contributor to depression, anxiety and impaired QoL was negative consequences, which have been repeatedly documented as a strong predictor of health outcomes.[17,20,21,24,27,41,42] BIPQ emotional response was significantly associated with anxiety and impaired QoL, whereas treatment control explained significant variance in depression and impaired QoL, which is consistent with other studies.[17,27] Surprisingly, concern beliefs showed a different trend in the regression analyses, with higher concerns significantly contributing to a reduction in anxiety levels. This relationship may have been indirectly influenced by a third variable, which should be investigated in future studies.

These findings have important clinical implications. Practitioners have the potential to make a positive contribution to patients' psychological well-being and QoL by routinely assessing their illness perceptions rather than focusing solely on the clinical symptoms of their skin condition. Illness perceptions have been shown to be modifiable by brief psychoeducational programmes in other long-term conditions, with subsequent improvement in patient outcomes including depression, anxiety, QoL and disease symptoms.[43–46] Given the higher incidence of depression and the lower QoL found in patients with HS compared with other dermatoses,[8,9,11] it is of great importance to help people with HS deal with their unhelpful illness beliefs, such as perceived lack of treatment control over HS, perceived negative consequences, and their emotional reactions to the disease. When designing interventions for HS, it is crucial to take into account the considerable

variation in illness perceptions found in the present study, as it has been previously.[37]

We acknowledge that the study's cross-sectional design does not provide evidence of causality but only reveals associations among the variables. Prospective longitudinal studies can help examine patients' variability in illness perceptions and how they influence health outcomes over time. Additionally, participants were recruited from a single teaching hospital in London and therefore the sample might not represent the whole HS spectrum, compromising the generalizability of the findings. Future research should include patient beliefs about what causes HS, as it is one of the most modifiable illness perceptions.[27] Studies could also build on the results of this study and examine coping mechanisms and resilience in patients with HS along with how they might affect health outcomes, which has been touched upon previously.[47,48] Finally, it will be interesting to see whether the results are replicated when employing dynamic HS scoring systems such as the International Hidradenitis Suppurativa Severity Score System,[49] and how illness perceptions relate to other validated and skin-specific subjective measures of disease burden such as PRISM (Pictorial Representation of Illness and Self Measure).[50–52]

In conclusion, illness perceptions in patients with HS, rather than disease severity, showed consistently greater and more significant associations with depression, anxiety and QoL. This suggests that health professionals should target negative perceptions and emotions about the disease in treatment programmes. Further research is needed to assess the effectiveness of interventions aimed at altering unhelpful beliefs in patients with HS and their benefits in managing their condition.

Acknowledgments

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Supporting Information

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

Table S1 Summary of the hierarchical multiple regression analysis explaining depression scores.

Table S2 Summary of the hierarchical multiple regression analysis explaining anxiety scores.

Table S3 Summary of the hierarchical multiple regression analysis explaining impaired quality-of-life scores.

Powerpoint S1 Journal Club Slide Set.