ORIGINAL REPORT

Development and Validation of a Disease-specific Outcomes Tool for the Assessment of Patient Benefits of Treatment for Hidradenitis Suppurativa: the PBI-HS

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Hidradenitis suppurativa is a chronic skin disease associated with significant disease burden. To assess patients' treatment benefits, disease-specific outcomes measurement is needed. This study aimed to develop a questionnaire called Patient Benefit Index for hidradenitis suppurativa (PBI-HS). After an open-item survey, the items were condensed into a 26-item questionnaire on patient needs and benefits, with a 5-point Likert scale. In the validation study, construct and content validity, responsiveness, and feasibility of the questionnaire were assessed at 2 time points. A 26-item questionnaire was created following open-item generation by $n = 72$ patients. In the validation study, 3 items perceived as most relevant by patients were: "to be free of pain" (mean: 3.6 on a scale of 0–4), "to be free of inflammation" (mean: 3.6), "to have no more scars" (mean: 3.1). Significant correlations of PBI-HS at follow-up visit were found with the physical global assessment for hidradenitis suppurativa (HS-PGA) ($r = -0.471$; $p = 0.000$), number of inflammatory lesions ($r = -0.359$; $p = 0.005$), and DLQI ($r = -0.383$; $p = 0.003$), indicating less disease burden in patients with higher treatment benefits. The PBI-HS is a feasible and valid instrument to assess patient-reported treatment benefits in hidradenitis suppurativa.

Key words: hidradenitis suppurativa; life quality; patient outcome assessment; patient-reported outcomes.

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SIGNIFICANCE

The Patient Benefit Index for hidradenitis suppurativa is a unique disease-specific instrument for recording the patient-side benefit of therapy in patients with hidradenitis suppurativa. No other instrument allows patients to clearly define their personal needs for therapy prior to treatment, from which the achievement of these personal goals can then be calculated. In this way, the personal patient perspective is placed at the centre of attention. This concept has already proven successful in the case of psoriasis.

Hidradenitis suppurativa (HS) is a chronic inflammatory skin disease characterized by recurrent inflammatory lesions and scarring (1). Prevalence figures vary widely and depend on the methodological approach used (2, 3). An analysis conducted by Kirsten et al. in German working individuals, for example, showed a prevalence of inflammatory and non-inflammatory lesions associated with HS of 3% (4). A strong diagnostic delay of 7.2 ± 8.7 years indicates that awareness of the disease is not yet widespread among healthcare professionals (5).

Clinically, HS is characterized by the appearance of abscesses, inflammatory nodules, or draining tunnels, especially in body folds (1). The inflammatory lesions can develop overnight and are associated with numerous stresses for the affected person and their family members. In addition to pain, people with HS suffer from secretion and unpleasant odour, itching, restricted mobility, and loss of sleep due to pain (6–8). In addition to physical limitations, there are numerous psychosocial burdens. Individuals with HS are more likely to suffer from depression or anxiety disorders than the general population (9). Social isolation is common, as is sexual dysfunction. Thus, it is not surprising that the losses in quality of life for affected individuals are higher than in most other dermatoses and in non-dermatological chronic conditions (10).

For the assessment of disease burden in HS, numerous measurement tools have been used (11), including the Dermatology Life Quality Index (DLQI) (12), Skindex (13), and condition-specific instruments such as the HS quality-of-life measure (HS-QoL) (14).

In addition to the concept of disease burden, there is growing use of outcome tools that address patient needs and subsequent patient benefits from treatment (15). This form of goal attainment scaling reflects goal- and patient-oriented healthcare in practice. The Patient Benefit Index (PBI), the most frequently used goal attainment measure in dermatology, is a tool for assessing patient-defined

benefits from treatment. It has been used in a variety of indications, including psoriasis (16), atopic dermatitis (17), chronic wounds (18), and vascular diseases (18). The PBI instrument first addresses the physical and psychosocial needs of patients by recording patient needs before therapy (Patient Needs Questionnaire [PNQ]), followed by measuring the achievement of treatment goals during or after treatment (Patient Benefit Questionnaire [PBQ]). Additionally, to evaluate outcomes on individual items, a total Patient Benefit Index (PBI) is generated, which reflects the overall treatment-related benefit to a single patient.

To date, no specific version of a patient benefit tool for HS has been available. The aim of our study was to develop and validate a disease specific PBI for individuals with HS.

MATERIALS AND METHODS

Item selection and development of the Patient Benefit Index for hidradenitis suppurativa questionnaire

The Patient Benefit Index for HS (PBI-HS) was developed in 2 phases according to the German recommendations for the development of psychometric measurement instruments (19). In the first phase, patients with any type and severity of HS in 1 Swiss (Zurich) and 4 German (Hamburg, Bochum, Frankfurt, Dessau) HS centres were included in a survey with open questions in German concerning their disease burden and potential treatment goals related to HS. In the second phase, the collected items were sorted thematically and condensed into a disease-specific questionnaire by an expert panel consisting of 2 dermatologists specialized in HS, 2 psychologists, and 2 patients. The collected items were condensed into a 26-item questionnaire. The items were linguistically adapted after cognitive interviews. According to an iterative process, 5 patients were interviewed by a researcher.

The resulting items were included in the 2 standard parts of the PBI: the PNQ, which is used before the start of therapy, and the PBQ, to be applied during the course of treatment. Both the goal importance rating and the evaluation of the extent to which the needs have been met are based on a 5-point Likert scale (0 = "not important at all" and 4 = "very important" or 0 = "therapy has not helped at all" and 4 "therapy has helped a lot"). Patients also have the option to tick "does not apply to me", in which case the goal is not included in the total score. For the calculation of the total score, the partial sums of all items, weighted by their patient-rated importance, are calculated and added. The maximum possible value reflecting maximum benefit is 4, and the lowest value is 0, indicating no therapeutic benefit at all.

Ethical approval was obtained from the competent authority prior to implementation.

Validation study

Data were obtained in a prospective multicentre observational study conducted at 4 German (Hamburg, Bochum, Frankfurt, Dessau) specialized HS centres. Each centre was tasked with consecutively recruiting at least 10 adult patients with HS of any severity and phenotype before starting a new treatment (antibiotics or biologics) until a total of 100 patients was achieved. Data were collected at baseline (T1) and at a follow-up visit (T2) after 4–12 weeks of treatment.

Disease severity

To determine clinical disease severity, the number of inflammatory lesions (20), the Physician Global Assessment for Hidradenitis Suppurativa (HS-PGA) (20), and the Hurley stage were assessed. The assessment of the lesions was performed clinically; ultrasound examination was not used.

Health-related quality of life and health state

Dermatology-specific quality of life was measured using the Dermatology Life Quality Index (DLQI). The generic health-related quality of life was assessed using EQ-5D-5L (21). The generic health state was evaluated using the EQ-VAS on a scale from 0 (worst health imaginable) to 100 (best health imaginable).

Patient Benefit Index for hidradenitis suppurativa validation analyses

To describe the psychometric properties of the PBI-HS, the following analyses were performed:

1. Item distribution (frequency, mean, standard deviation of the single items and the PBI global score).
2. Internal consistency of the PNQ, measured by Cronbach's alpha, content validity.
3. Ceiling and floor effect (CFE).
4. Construct validity.
5. Responsiveness.
6. Factor analyses.
7. Feasibility and patient acceptance.

Feasibility and acceptability of the questionnaire were surveyed using a 1-page questionnaire. The following data were collected: completion time, understandability of the questions, whether any important questions were missing, difficulties in deciding on an answer, and length of the questionnaire. There were always 2 answer options (yes or no), with the exception of the time taken to complete the questionnaire. Patients were also given the opportunity to provide reasons for their answers in an open form.

CFE was computed to calculate the effect of potential bias or uncertainty (22). Overall, the degree of uncertainty in a statistical method increases proportionally with the CFE, and the robustness decreases. The distribution was calculated for both the PNQ and the PBI.

Construct validity was assessed by correlating (Pearson correlation) the PBI-HS with other patient-reported and clinical endpoints at T2 (HS-PGA, number of inflammatory lesions, EQ-5D and DLQI).

To determine the change sensitivity of the PBI-HS, the correlation between PBI total score at T2 and the DLQI total score at T2 was calculated, statistically controlling for DLQI total scores at T1.

The cut-off value for the PBI measurement instrument was scientifically developed. The development process has been described in detail in previous publications (23).

Factor analysis

The dimensions of the PBI-HS were determined using exploratory factor analysis. Factor analysis was performed using the PNQ items with varimax rotation. The answers "does not apply to me" or "not at all" were classified as irrelevant parameters and not included in the factor analysis. Only factors with a value higher than 1 were extracted. The individual items were assigned to the factors on which they loaded most highly. Cronbach's alpha was calculated to determine internal consistency of the resulting subscales.

Analyses were conducted using SPSS Version 26.0 (IBM Corp, Armonk, NY, USA) for Windows.

RESULTS

Development of the Patient Benefit Index for hidradenitis suppurativa questionnaire

Seventy-two patients took part in the open question survey. The mean age was 40.4 (SD: 11.4 years), and 58.3% were male.

Validation study

Patients and clinical outcomes. A total of 101 patients participated in the validation study. The mean age was 38.1 (SD: 12.0 years), and 69 patients (68.3%) were female. The mean disease duration was 6.1 ± 9.1 years. Among the patients, 22 patients (21.8%) had Hurley stage 1, 56 (55.4%) had Hurley stage II, and 23 (22.8%) had Hurley stage III. At the first time point, the mean HS-PGA was 2.7 (SD: 1.1), the mean number of inflammatory lesions was 6.0 (SD: 6.6), and mean DLQI was 11.5 ± 6.8. Some 36% (n = 37) of patients were treated with long-term antibiotic therapy, 35.6% (n = 36) with biologics, and 29.7% (n = 30) with topical treatment.

Item characteristics of the Patient Benefit Index for hidradenitis suppurativa

Patient Needs Questionnaire. The mean item values (scale from 0–4) ranged from 1.5 for "to have no more financial worries" to 3.6 for both "to be free of pain" and "to be free of inflammation" (**Table I**). The 6 most relevant items for the patients were: "to be free of pain" (mean: 3.6), "to be free of inflammation" (mean: 3.6), "to have no more scars" (mean: 3.1), "to feel less depressed" (mean: 3.1), "to have no more deformation" (mean: 3.1), and "to lead a normal everyday life" (mean: 3.1). The item for which the statement "does not apply to me" was made most frequently was "to have no more financial worries" (24.8%).

Overall, the response rate of "does not apply to me" ranged from 1% to 24.8%. However, each item was considered important ("important" and "very important") for at least 29.7% of the participants. The highest number of missing values was found for the items "to sleep better" (n = 5) and "to have fewer out-of-pocket treatment expenses" (n = 5). Nevertheless, the missing rate was very low (< 5% for all items).

Patient Benefit Index

The mean PBI was 2.02 (range: 0–4; median: 1.95). There was no CFE (PBI = 0 in 5.0% and PBI = 4 in 3.0% patients), and the distribution was largely homogeneous across the scale (**Fig. 1**).

Assuming a PBI cut-off of 1, 78.7% of patients achieved a relevant patient benefit from the treatment used (24).

Table I. Distribution of PNQ items and allocation to the subscales 'psychosocial'/'physical' in n = 101 patients

PNQ items	Treatment goal/patient need	Missing values, n	Mean	SD	% (n) "important" or "very important"	% (n) "does not apply to me"	Factor "psychosocial"[a]	Factor "physical"[b]
1	Be free of pain	2	3.6	0.9	89.1 (90)	1 (1)	0.347	0.470[b]
2	Be free of itching	2	3.0	1.3	68.3 (69)	5.9 (6)	0.185	0.788[b]
3	Be free of unpleasant smells	4	3.0	1.5	72.3 (73)	8.9 (9)	0.004	0.811[b]
4	Be free of oozing from the skin	1	3.0	1.4	70.3 (71)	9.9 (10)	−0.072	0.704[b]
5	Be free of inflamed skin	4	3.6	0.9	90.1 (91)	1 (1)	0.281	0.365[b]
6	Be able to sleep better	5	2.4	1.6	56.4 (57)	15.8 (16)	0.555[a]	0.316
7	Be able to sit without discomfort again	2	2.7	1.6	64.4 (65)	13.9 (14)	0.479[a]	0.185
8	Be less restricted in your ability to move around	3	3.0	1.3	74.3 (75)	6.9 (7)	0.506[a]	0.463
9	Be free from further scars	2	3.1	1.3	71.3 (72)	3 (3)	0.428[a]	0.272
10	Experience a greater enjoyment of life	2	3.1	1.4	77.2 (78)	8.9 (9)	0.817[a]	0.187
11	Be free from shame	3	2.8	1.5	68.3 (69)	6.9 (7)	0.614[a]	0.315
12	Be free from fear	2	2.4	1.6	54.5 (55)	9.9 (10)	0.773[a]	−0.010
13	Be free of financial worries	3	1.5	1.7	29.7 (30)	24.8 (25)	0.502[a]	0.131
14	Not feel helpless	3	2.5	1.6	61.4 (62)	9.9 (10)	0.718[a]	−0.063
15	Be free of any more disfigurements	3	3.1	1.3	75.2 (76)	4 (4)	0.604[a]	0.190
16	Be able to lead a normal everyday life	3	3.1	1.4	75.2 (76)	5 (5)	0.764[a]	0.242
17	Be able to spend time with others	2	2.4	1.7	56.4 (57)	14.9 (15)	0.763[a]	0.120
18	Be less burdened in your partnership	2	2.6	1.7	60.4 (61)	17.8 (18)	0.622[a]	0.316
19	Be able to have a normal sex life	2	3.0	1.5	72.3 (73)	9.9 (10)	0.671[a]	0.245
20	Be able to pursue normal leisure and sports activities	2	2.9	1.3	73.3 (74)	5 (5)	0.556[a]	0.390
21	Not gain weight	2	2.7	1.6	65.3 (66)	10.9 (11)	0.459[a]	0.416
22	Need less time for daily treatment	4	2.2	1.5	48.5 (49)	9.9 (10)	0.744[a]	0.317
23	Have fewer out-of-pocket treatment expenses	5	1.9	1.7	41.6 (42)	10.9 (11)	0.602[a]	0.242
24	Be less dependent on help from others	2	1.8	1.7	38.6 (39)	14.9 (15)	0.751[a]	0.058
25	Be able to take care of yourself normally	2	2.4	1.6	52.5 (53)	13.9 (14)	0.732[a]	0.205
26	Have fewer side effects	2	2.1	1.8	50.5 (51)	19.8 (20)	0.444[a]	0.440

[a]Allocation to cluster 1: psychosocial burden. [b]Allocation to subscale 2: physical burden.

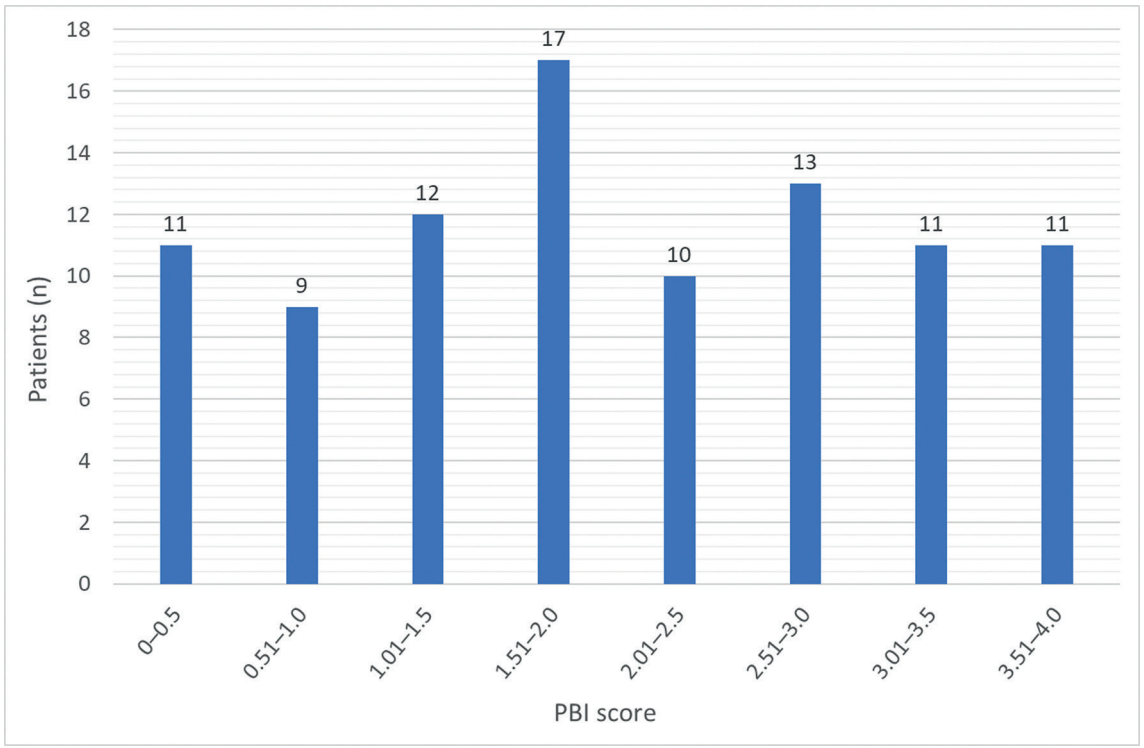

Fig. 1. Distribution of PBI (patient benefit index) mean values in categories (0 = no benefit; 4 = maximum benefit; *n* = 94).

Construct validity

Significant negative correlations of the PBI-HS total score were found with HS-PGA (r=-0.471; p=0.000), number of inflammatory lesions (r=–0.359; p=0.005), and with DLQI (r=–0.383; p=0.003) at T1. The PBI total score did not show significant correlations with EQ-5D (r=0.226; p=0.088) and Hurley stage (r=–0.243; p=0.063).

Responsiveness

The sensitivity to change of the PBI-HS with regard to change in the DLQI was significant (r=–0.0396; p=0.000).

Structural validity

No missing values were found in 88 patients who were included in the exploratory factor analysis. The rotational analysis indicated that the items could be allocated to 2 factors in a way that made sense in terms of content. PNQ items 1–5 (factor 1) could be assigned to physical symptoms, and PNQ items 6–26 (factor 2) could be assigned to resulting psychological and physical distress (Table I). Two factors with an eigenvalue > 1 explained 47% of the variance. Cronbach's alpha for the 2 factors was 0.70.

Feasibility and patient acceptance

There was a high level of acceptance of the PBI-HS by the patients. The rate of missing values was low (< 5%) for each item. The purpose of the questionnaire was clear to 94.1% (n=95) of participants. Additionally, 94.1% (n=95) felt that the instructions for the questionnaire were comprehensible, 95% (n=96) rated the individual items as understandable, and 2% (n=2) stated that important goals were missing.

DISCUSSION

In this study, we assessed the psychometric properties of the newly developed Patient Benefit Index for HS (PBI-HS) in a large cohort of patients with moderate to severe HS. Our findings confirm that the PBI-HS is a reliable, valid, and feasible instrument for assessing patient-relevant treatment outcomes in HS.

Psychometric properties of the PBI-HS

The internal consistency of the PBI-HS was found to be acceptable, with a Cronbach's alpha of 0.70 for the 2 factors identified in the factor analysis, suggesting that the instrument reliably measures a coherent construct. The factor analysis indicated that the PBI-HS comprises 2 distinct dimensions: physical symptoms (e.g., pain, inflammation) and psychological distress (e.g., depression, anxiety, social impacts). These 2 factors are consistent with the understanding that HS is not only a physical condition but also a source of significant psychological burden, aligning with findings from previous studies that emphasize the multidimensional nature of HS (8, 9).

The construct validity of the PBI-HS was confirmed by its significant negative correlation with the HS-PGA, the number of inflammatory lesions, and the DLQI, indicating that higher levels of patient-reported benefit were associated with improvements in disease severity and quality of life. This further supports the notion that the PBI-HS captures meaningful changes in patient outcomes following treatment. The absence of a strong correlation with the EQ-5D may reflect the more disease-specific nature of the PBI-HS, which is designed to capture HS-specific outcomes that may not be fully reflected by generic quality of life measures.

The PBI-HS demonstrated good responsiveness to changes in disease severity, as evidenced by its significant correlation with changes in DLQI scores. This suggests that the PBI-HS is sensitive to changes in patient status over time and can effectively track the impact of therapeutic interventions. The absence of ceiling or floor effects further supports its sensitivity, as the instrument is able to capture a wide range of patient experiences without being biased toward extreme values.

In this study, we did not include the Hidradenitis Suppurativa Clinical Response (HiSCR) as a measure of HS severity. However, this instrument is required by the FDA for every pivotal trial. Achieving an HiSCR50 response is considered a classic primary endpoint. HiSCR is an instrument that determines the clinical severity of the disease based on the count of inflammatory lesions. However, the HiSCR is not achieved if a tunnel or abscess develops during the course of treatment. This is a decisive limitation of this score. Patient-centred questionnaires, such as the PBI-HS, could be used as a supplement to better correlate the patient's benefit from an intervention with the clinical response. This would provide a more complete approach to assessing the achievement of treatment goals.

Feasibility and acceptability

The PBI-HS was well received by patients, with high ratings for understandability, relevance, and ease of completion. The low missing data rate and minimal time required to complete the questionnaire underscore its practicality in clinical settings. This is particularly important, as the successful integration of patient-reported outcomes (PROs) into routine clinical practice hinges on the feasibility and patient acceptance of the instrument. The PBI-HS meets these criteria, making it a promising tool for regular use in monitoring HS treatment outcomes.

Limitations

While our study provides robust evidence for the psychometric properties of the PBI-HS, there are several limitations to consider. The sample was drawn from 4 specialized HS centres, which may limit the generalizability of the findings to other populations, particularly those seen in primary care or less specialized settings. Additionally, the study focused on adults, and the PBI-HS has not been validated in paediatric populations. Further studies are needed to evaluate the performance of the PBI-HS in diverse settings and across different age groups.

Moreover, while the PBI-HS was able to capture important patient-relevant outcomes, the instrument did not include aspects such as treatment satisfaction or out-of-pocket costs, which may also influence patients' overall assessment of benefit. Future iterations of the PBI-HS could consider integrating additional domains to provide a more comprehensive measure of treatment impact.

Clinical implications

The PBI-HS can serve as a valuable tool in clinical practice and clinical trials, offering a patient-centred approach to assessing treatment benefit. Its focus on patient-reported outcomes provides insights into the physical and psychological burden of HS, offering a more holistic view of the patient's experience than traditional clinical measures alone. The ability to track changes in patient benefit over time could help clinicians make more informed decisions on treatment adjustments, particularly in cases where disease severity may not fully reflect the patient's perceived quality of life.

In clinical trials, the PBI-HS could serve as an important endpoint for evaluating the effectiveness of new therapies, allowing for a more nuanced understanding of how treatments impact patient-relevant outcomes. Given the multidimensional nature of HS, a single composite measure like the PBI-HS that encompasses both physical and psychological aspects may be more sensitive to therapeutic changes than existing instruments.

Conclusion

The PBI-HS is a valid, reliable, and feasible tool for assessing the patient-reported benefit of treatment in individuals with HS. By capturing both physical and psychological dimensions of the disease, it provides a comprehensive measure of treatment impact that is directly relevant to patients. Its high acceptability and low missing data rate make it a practical choice for routine clinical use and for incorporation into clinical trials. As such, the PBI-HS has the potential to improve the management of HS by helping clinicians better understand the outcomes that matter most to patients and by informing treatment decisions that are aligned with patient priorities.

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