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Hidradenitis suppurativa burden of disease tool: Pilot testing of a diseasespecific quality of life questionnaire

To the Editor: Hidradenitis suppurativa (HS) is a chronic inflammatory condition affecting intertriginous areas of the body that dramatically impairs quality of life (QoL) and has a substantial psychosocial burden.^{1,2} Full remission of HS is rare, making improvements in QoL a critical goal of therapy. Currently, when investigating the impact of HS, we are limited to generic QoL questionnaires, none of which are specific for HS. We propose a disease-specific tool that would better capture the unique burden of disease caused by HS, which is necessary to determine the impact of therapeutic interventions in clinical trials and in the clinical setting.

We used both consensus expert opinion from 8 medical dermatologists and patient input to develop the Hidradenitis Suppurativa Burden of Disease (HSBOD) tool (Supplemental Material; available at http://www.jaad.org). The HSBOD is a 19-item selfadministered visual analog scale (VAS) questionnaire designed to provide a more nuanced and accurate understanding of the overall burden of disease among patients with HS. Questions in this novel tool include a 10-cm VAS ranging from 0 (no complaints) to 10 (worst complaints). VASs have been validated, making survey completion rapid and easy while yielding more precise responses; however, the HSBOD requires abstract thinking, which may be difficult for some patients.^{3,4} We compared HSBOD tool performance to the commonly used, non-disease-specific Dermatology Life Quality Index (DLQI). HSBOD questions were divided into 5 domains: "symptoms and feelings," (questions 1-9 and 17) and impact upon "daily activities," (questions 10 and 13) "leisure," (questions 11, 13, and 14) "work/school," (questions 12, 18, and 19), and "personal relationships" (questions 6-9, 15, and 16). Twenty-nine patients (none of whom participated in tool development) with HS who were diagnosed by a Board-certified dermatologist completed both surveys without assistance.

The reliability, or the degree to which the HSBOD produces stable results, was assessed by Cronbach alpha.⁵ Cronbach alpha of 0.936 for this study indicates good internal consistency within the HSBOD. The median HSBOD score was 5.5 of 10 and the median DLQI was 13 of 30. Spearman rho was calculated as a measure of the strength of the rank correlation between HSBOD and DLQI. Individuals' HSBOD scores were plotted against corresponding DLQI scores for the overall summary score and subscales (Fig 1). Questions on the HSBOD corresponding to "symptoms and feelings" $(\rho = 0.681, P < .001)$, "leisure" $(\rho = 0.661, P < .001)$, and "daily activities" ($\rho = 0.598, P < .001$) had a strong correlation to the corresponding DLQI subscales. HSBOD questions corresponding to "personal relationships" ($\rho = 0.419, P = .024$) and "work/ school" ($\rho = 0.310, P = .101$) had a moderate correlation with the corresponding DLQI questions, although the "work/school" domain did not achieve statistical significance. The lack of a strong correlation between the HSBOD and DLQI for "personal relationships" and "work/school" may reflect that the HSBOD has several questions designed to specifically investigate issues in HS, while the DLQI has fewer generic questions for all skin disorders. We feel this lack of correlation could represent shortcomings of the DLQI in fully capturing the many facets of HS contributing to the burden of disease.

Although our study is limited by the small sample size and likely increased disease severity among patients in a tertiary care referral center, the HSBOD questionnaire shows internal reliability and correlates strongly ($\rho = 0.604$, P < .001) with a validated nonspecific skin QoL tool (the DLQI). Future studies with broader data collection should confirm item selection, validity, and reliability of HSBOD considering the lower item-scale correlations for a subset of the 19 items.

We thank the patients who have graciously accepted to complete the surveys. Without their participation, this study would not have been possible.

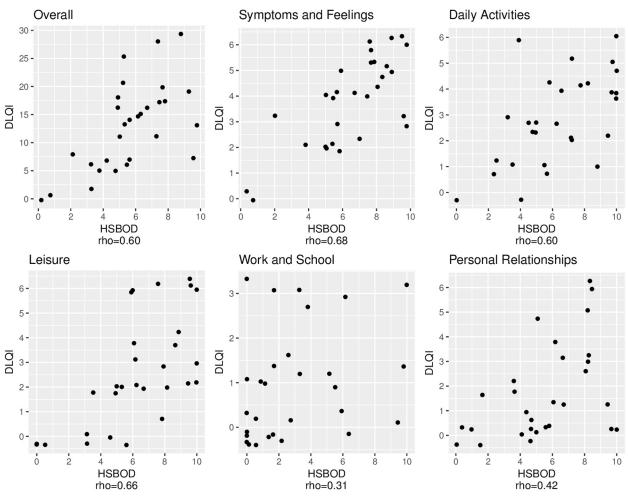


Fig 1. Scatterplots of Dermatology Life Quality Index and Hidradenitis Suppurativa Burden of Disease overall scores and subscales. Individuals' Hidradenitis Suppurativa Burden of Disease scores were plotted against corresponding Dermatology Life Quality Index scores for the overall summary score and subscales. Spearman's rho was calculated as a measure of the strength of the rank correlation between the 2 scales.

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