



ACNE, ROSACEA, AND RELATED DISORDERS (INCLUDING HIDRADENITIS SUPPURATIVA)

QOL-HS: NEW INSTRUMENT TO ASSESS QUALITY OF LIFE IN PATIENTS WITH HIDRADENITIS SUPPURATIVA

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Background: Hidradenitis suppurativa is a chronic, debilitating skin disease with a high impact on quality of life. Assessment of disease related impairments in quality of life in patients with hidradenitis suppurativa (HS) requires specific tools.

Objective: The aim of our project was to develop and validate a measuring instrument to assess disease specific quality of life instrument for patients with HS.

Materials and Methods: In the initial phase, n = 72 patients with HS were asked in an open text form about their burden of disease and treatment needs. We collected the items and classified them in subgroups. The item pool thus generated was reviewed by a panel of dermatologists, psychologists and patients and transferred to a 26-item questionnaire. Each item was examined for its representativeness and its suitability. The validation study of the questionnaire is now ongoing in n= 100 patients.

Results: We collected 34 different items for the question “the burden of disease“. Top five of identified disease burden were: Pain (n=41; 57%), restrictions in social life (n=34; 47%), psychological burdens (n= 34; 47%), limitations in mobility (n= 30; 41%) and restrictions in spare time activities (n=24; 33%). Top five of patient related treatment needs were reduction of pain (n=51; 71%), no more limitations in mobility (n=31; 43%), no more inflammation (n=9; 12%), reduction of scars (n=6; 8%) and weight loss (n=3; 4%).





Conclusions: QoL-HS is a new instrument to assess disease specific quality of life in patients with HS. The development of disease related measurement tools is an important step to improve the care of patients with HS.

