

LETTER TO THE EDITOR

HIDRADisk: an innovative visual tool to assess the burden of hidradenitis suppurativa

Editor

Hidradenitis suppurativa (HS) is a chronic relapsing inflammatory dermatosis of the body folds, characterized by nodules, abscesses, sinus tracts and numerous comorbidities, significantly impairing patients' quality of life (QoL).^{1–5} Among skin diseases, HS has the largest impact on QoL.⁶ Few specific instruments are available to assess, in a comprehensive, psychosocial perspective, the burden of HS,⁷ and no qualitative studies exploring the experience of HS patients and their relationship with the physician are currently available.

As for PSODisk,⁸ the development of HIDRADisk was based on the assumption that the use of visual instruments, completed by the patient together with the dermatologist, might foster verbalization of the main disease-related aspects relevant for patients, facilitating the patient–physician relationship and conveying some feeling of control over the course of the disease.

A mixed methodology has been applied: patient-only and a physician-only focus groups⁹ were created to capture the experience and perspective of the disease on both sides; a modified Delphi method¹⁰ was then applied to assess the level of convergence of both opinions about the items selected and their weight within the disease experience of HS.

A clinical psychologist, acting as facilitator, conducted two distinct roundtable meetings: one included nine patients (6 women; aged 19–55 years) affected by HS for ≥ 24 months, while the other roundtable meeting included ten dermatologists (6

Table 1 Delphi panel dimensions/items and patients' and dermatologists' agreement

Dimension	Item	Level of agreement among patients (%)	Level of agreement among dermatologists (%)
General state of health	Dramatic impairment of QoL	100	100
	Impairment of capability of making projects for the future	78	90
	Disruption of regular physical activities like sports	100	90
Daily activities	Impairment of personal autonomy	100	90
	Impairment of daily domestic activities	78	70
Pain	Pain is the main symptom of the disease	78	100
	Pain is very intense	100	100
	Pain the symptom of the disease which mostly influences all aspects of my life	100	90
Odour	Smell is the main symptom of the disease	78	100
	Smell is a most disagreeable experience	100	100
	Smell is the aspect of disease which most impacts on QoL	78	100
Self-efficacy (ability to control the disease)	HS induces the feeling to be prey to a capricious and unforeseeable disease	100	100
	HS induces the feeling of being prey to symptoms such as pain and smell which are uncontrollable	100	100
	HS does motivate you to do all which is helpful to keep the disease under control	67	100
Self-image	HS influences the personality of the patient by pushing the patient never to be at full ease with her/himself	78	100
	HS influences the personality of the patient by experiencing herself/himself as a less pleasant/desirable person	NS	100
	HS influences the personality of the patient by making her/him feel less confident in interacting with other people	78	90
	HS influences the personality of the patient by making her/him unfit to face any situation she/he may be confronted with	100	90
	HS influences the personality of the patient by making her/him more apathetic or sad	100	100
	HS influences the personality of the patient by making her/him more short-tempered or aggressive	78	90

Table 1 Continued

Dimension	Item	Level of agreement among patients (%)	Level of agreement among dermatologists (%)
Social life	HS reduces the frequency by which one meets relatives or friends	67	90
	HS induces avoiding to make new acquaintances	NS	90
	HS induces avoidance of public spaces such as movies theatres, sport events, gyms and swimming pools	NS	100
	HS enhances the tendency to dedicate oneself to pastimes and amusements that can be performed alone (such as computer games)	NS	100
Work	HS is a disease exerting a negative influence on work by requiring frequent sick leave	89	100
	HS is a disease exerting a negative influence on work by impairing good interaction with colleagues (for instance, because of the frequent absence or the smell)	78	100
	HS is a disease exerting a negative influence on work by making advancements in career less likely	67	90
	HS is a disease exerting a negative influence on work by impairing the maintenance of the level of attention and efficiency required by the daily work	78	90
Sexuality	HS impacts on the sentimental and sexual life of patients by pushing patients to avoid opportunities of meeting potential partners	78	100
	HS impacts on the sentimental and sexual life of patients by inducing patients to accept situations of intimacy only when the disease is not active	78	100
	HS impacts on the sentimental and sexual life of patients by moving patients to give up the idea of having a normal sentimental/ sexual life	78	100
Doctor–patient relationship	HS is not only a severe but also a chronic disease and an ideal patient–physician relationship should allow the patient to be told as early as possible the diagnosis and to understand the main features of HS	100	100
	HS is not only a severe but also a chronic disease and an ideal patient–physician relationship should allow the patient to receive adequate information on the available options for therapy	100	100
	HS is not only a severe but also a chronic disease and an ideal patient–physician relationship should allow the patient to be met and understood not only as a patient but also as a person	100	90
	HS is not only a severe but also a chronic disease and an ideal patient–physician relationship should allow the patient to access a network of dedicated structures within the whole country	100	90

HS, hidradenitis suppurativa; NS, not-solved: items with a low percentage of agreement in terms of consensus; QoL, quality of life.

women) with well-documented experience in the research field of the impact of chronic skin diseases on QoL. Both patients and physicians were deeply interested in the development of a new tool, had knowledge of HS and were motivated to share their knowledge and experience.

The first endpoint was to identify the most significant aspects of the patients' experiences, with the purpose of selecting the questionnaire items. During the meetings, questions were asked by a facilitator regarding patients' emotions, interpretations and expectations related to HS and the impact of the disease on daily life and social relationships. Items were divided into 10 dimensions; each dimension encompassed 2–6 items for a total of 35 items. Patients and physicians were asked to express their degree of consent on each statement using a 5-point Likert scale (1 = highest disagreement to 5 = complete agreement). A consensus was reached with an agreement of >66%. Items with a lower percentage of agreement were considered as 'not-solved'

in terms of consensus and eliminated (percentage of agreement shown in Table 1).

According to the results obtained by the Delphi procedure, the 10 identified dimensions were revised and only the items with a positive consensus from both patients and physicians were selected. A final meeting with 10 dermatologists chaired by a clinical psychologist acting as facilitator was held to discuss the results obtained. A rewording of the items was performed to further simplify and design an easy questionnaire (Fig. 1).

HIDRADisk is designed to be completed by the patient with the dermatologist, fostering their communication. Being a visual instrument, with the answers shown graphically through a polygon, HIDRADisk gives an immediate picture of the burden of the disease, allowing patients and physicians to visualize the course of the disease over time. When the burden of disease decreases, the area of the polygon shrinks, providing an immediate and intuitive representation of the progress achieved.

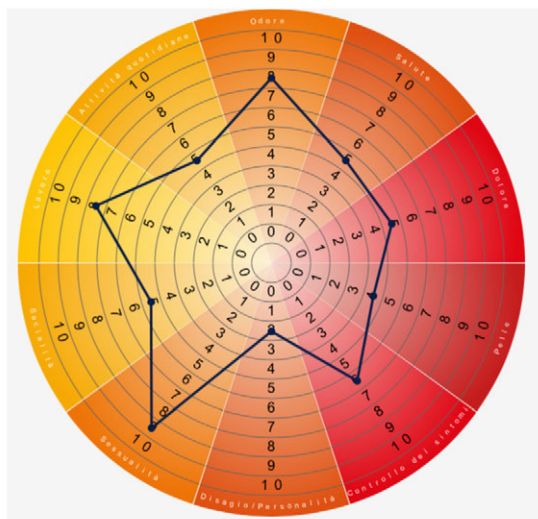


Figure 1 The HIDRADisk, with an example of a polygon derived by scores linked together and the relevant questions. *Skin*: HS affects my skin because of its extension or severity of symptoms or concerned areas; *symptoms control*: HS is an unpredictable disease, which is difficult to control; *uneasiness/personality*: HS makes me different from who I am (e.g. makes me insecure, inadequate, sad and aggressive); *sexuality*: HS impairs my sentimental and sexual life; *social life*: HS impairs my social life (e.g. meeting up with friends and family); *work*: HS impairs my working life (e.g. sick leave, difficult relationships with colleagues, reduced career opportunities and lack of concentration); *daily activities*: HS impairs my daily activities (e.g. domestic activities, personal care, sports and leisure, future planning); *odour*: HS causes me an unpleasant odour; *general health*: HS impairs my general state of health; *pain*: HS causes me physical pain.

HIDRADisk could help improve the management of the disease and increase patients' feeling of control over their disease.

HIDRADisk is currently under psychometric validation in 140 patients with different degrees of HS severity, correlating the HIDRADisk outcomes with the Dermatology Life Quality Index and the Skindex-16. The tool will be developed on electronic devices, offering dermatologist a quick and easy response during routine clinical practice or clinical studies.

AbbVie participated in the conduct and financial support of the project, as well as in interpretation of the results, review and approval of the manuscript.

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