

Unmet needs in hidradenitis suppurativa: patients' perspective on daily management and cosmetic cares

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Summary

Hidradenitis Suppurativa (HS) is a chronic debilitating inflammatory disease, affecting very sensitive areas, such as genitalia, axillae, and groins of mostly young people, with a female predilection. Signs and symptoms are devastating for patients' quality of life, joined with a history of diagnostic delay, and hidden suffering even to close relatives. The disease has gained an increasing interest, with the proposal of new efficacious medical treatment. Besides, cosmetic skin care is somewhat uncover. To challenge patients' own perspective, the proposal of a survey to the main Italian Association, named Inversa Onlus, pointed out a free access questionnaire, published on the website. One hundred fifteen patients listed the major causes of daily activities limitation from a cosmetic point of view, selecting six items: affected skin appearance; scars appearance; smell; perspiration; epilation; blemish dresses. A 5 points scale expressed the level of disturbance, and the most rated features resulted: skin overall appearance, followed by scars, dirty spots on dress and problems related to depilation, while lesions smell and perspiration problems were judged less important. Asking patients unveiled that physicians should also take care of main accessory, cosmetically oriented daily needs, suggesting dedicated lines of products to improve skin appearance, and social acceptability.

KEY WORDS: *hidradenitis suppurativa; acne inversa;*

quality of life; cosmetic issues; case report; unmet needs; patients' perspective.

Introduction

Hidradenitis Suppurativa (HS) is an uncommon debilitating inflammatory cutaneous disorder of the infundibular terminal follicles, characterized by recurrent painful abscesses, fistulation, sinus tract formation and extensive scarring in apocrine gland-bearing areas, thus including genitalia, and other very sensitive areas, such as axilla, inframammary areas, and buttocks (1). The course is chronic, and often progressive, affecting mostly young people, with a strong female predilection, thus producing a dramatic impact on the patients' quality of life (2-4), impairing everyday tasks, from sitting at work to sports, and social activities due to the pain, but also for the embarrassment of the malodorous discharges. Furthermore, the disease is neglect, with many physicians unaware of the condition and causing a diagnostic delay of about 7 years (5). If the medical community is unfamiliar with it, the social connotation is even blunt, stigmatizing a lack of hygiene, compelling patients to isolation and hide their suffering even to close relatives (1, 4).

Proper treatment is an actual challenge, with limited and unsatisfactory results (6). Although some progress are on development, such as the approval of biologic immune-modulators, mainly anti-tumor necrosis factor (TNF) alpha – blockers (6-8), for many patients the final resort remains widely ablative surgery (9).

Several studies have measured the impairment of life qualities by means of standardized questionnaires (2-4), but the aim of this study was to gather the very individual patients' opinion on their daily lives limitations, from a practical and cosmetic point of view. Thanks to the collaboration of the main Italian HS patients Association, named Inversa Onlus, a list of 6 unmet needs was selected and supplied to their social network for spontaneous answering and grading of disturbances.

Materials and methods

A free access questionnaire, published on the Inversa Onlus patients' association website, was supplied for voluntary adhesion to the study. Although we cannot exclude that a non HS-patients took part to the survey, the association subscribers accessed to the link with their personal credential. Several questions on

disease severity and diagnosis were supplied to indirectly assess that at list one dermatologist visit had been performed. Data were anonymous, with the clearly stated intent of results divulgation to the community, as part of the social activities of the patients' association not requiring ethical approval. Six items were suggested (affected skin appearance; scars appearance; smell; perspiration; epilation; blemish dresses) and patients asked to express which was much disturbing and graduate it according to a 5 points scale (1= a little; 2= mildly; 3= well enough; 4= a lot; 5= very much).

Results

One hundred fifteen patients, mean age 49 years, mainly woman (74%) answered in the time lapse of 30 days (Table 1). Only 4 persons (3,4%), reported to be under remission, while the majority reported active disease. Another general information to assess that the answers were pertinent to the scope of the survey was the disease duration, which was reported variable

from 6 months to 32 years, with a mean of 7 years, and age at diagnosis, which varied from 14 to 38 year-old, with a mean of 24 years of age. Results of the questionnaire are showed on Figure 1, and the most disturbing feature of the disease from a cosmetic point of view resulted the skin appearance, judged very much embarrassing (5 points) for the 59% of the patients. The second most disturbing item was the scars appearance, judged very much embarrassing for the 53.9% of the patients. Dirty spots on dress was considered very much embarrassing for the 33.9% of patients, followed by problems related to body hairs and depilation (28.7% of patients). The lesions smell and perspiration problems were judged less important, with only respectively the 23.5 and 14.8% of the sample rating very much embarrassing (5 points) these items. It is an interesting datum, if we consider that this kind of problems is the mainly covered by specific items of the dermatological quality of life questionnaire, and high compromising is considered typical of hidradenitis suppurativa patients. All items were considered embarrassing a lot for about 20% of the patients (4 points; range 19.1 –

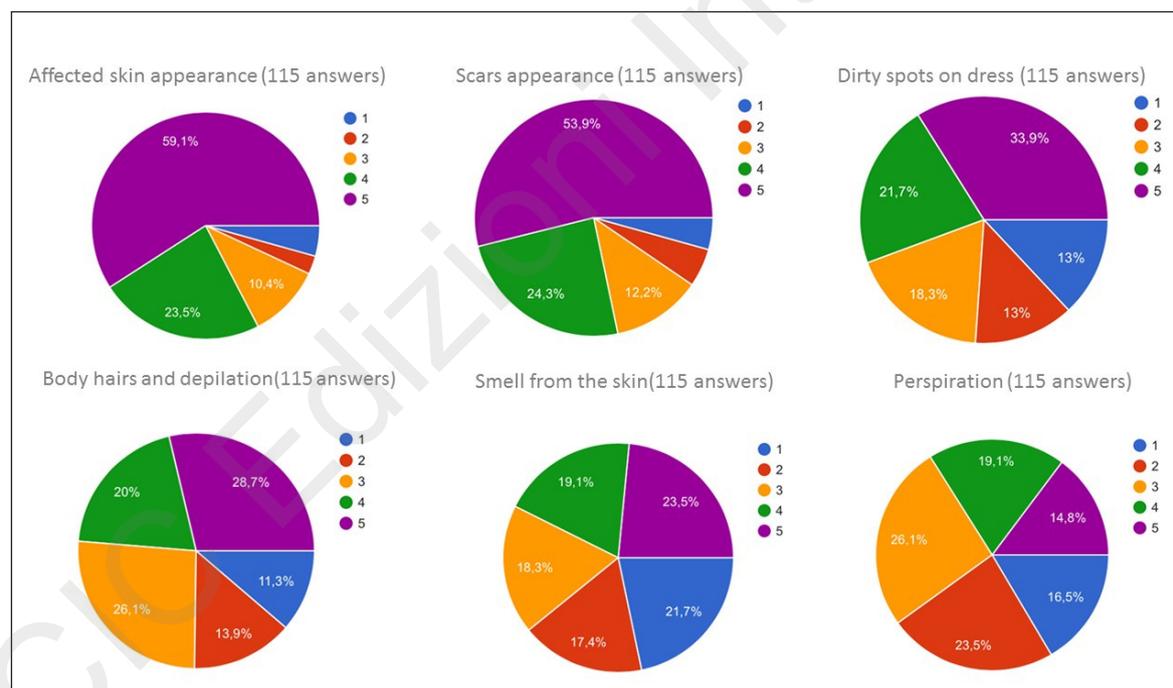


Figure 1 - The answers of the HS patients on the *Inversa Onlus* website are grouped for each suggested items (affected skin appearance; scars appearance; smell; perspiration; epilation; blemish dresses) and grade of disturbance (5 points scale; 1= little; 2= mildly; 3= well enough; 4= a lot; 5= very much).

Table 1 - Demography and disease characteristics of the persons answering to the questionnaire.

Persons answering	Sex	Mean age	Disease activity	Mean Disease duration	Mean Age at diagnosis
115	74% Female 26% Male	49 years	3.4% Under remission 96.6% Active disease	7 years	24 years

24.3%). Patients rating not very high the role of skin and scars appearance complained as well enough (3 points) troublesome depilation and perspiration (26.1%), followed by the skin lesions smell (18.3%).

Discussion

This survey focus on patients' opinion, asking about aspects of HS uncovered by current medical or surgical treatments, affecting daily cares and activities. The immediate and large consensus of a hundred of patients supports the levels of interest and participation to initiative dealing with the unmet needs, practical problems involving HS patients' quality of life. Although the subjects' number seems to be small to obtain any conclusion, the disease is uncommon, and most of all underreported, because of a lack of awareness and intention to treat, even in countries with easy access to healthcare services, such as Norway (10). Isolation and depression often make HS patients refuse to seek even their family support, and patients' Associations play a fundamental role against social alienation. Thus, voluntary participation to the study is an interesting result by itself, focusing the attention on some minor aspects, such as the skin appearance and scarring, malodourous perspiration, or dressing blemish, which usually are underrated as cosmetic issues. At least 4 of the proposed 6 items are not taken into consideration by the main official standardized quality of life questionnaire previously administered to HS patients, such as DLQI, and EQ-5D score (2, 3). Of course, patients' sufferance depends on the painful and disabling course of the disease, and only emerging new medical treatments will effectively change its natural history. Beside, cosmetic strategies to improve skin appearance might support primary medical and surgical interventions, collaterally working on dyschromia, texture, superficial scarring, blackheads as well as controlling smell and perspiration. Much of these unaesthetic problems persist after a good clinical response to the medical therapy, and scars usually limit the cosmetic acceptability of major surgery. Patients should fit to be seen in public to disrupt stigmatization, and social isolation. Medical community encourage HS patients to lose weight, make regular sport activities, but also recommend to avoid deodorant use, depilatory wax, close-fitting dress (1, 6). It is undoubtedly difficult to follow these recommendations, showing the marks and scars of the disease, wearing uncomfortable large clothing or with the fear of a stinky sweat. A number of skinceuticals might address safely and efficaciously these issues and other can expressly be designed for HS patients, effort that have been widely made for acne patients in recent years. The strength of the survey is the rapid success in the HS community, with a large adhesion, which prompt the Inversa Onlus association to translate the questionnaire in several languages and program the proposal to the European HS website to further collect and describe patients

unmet needs. Limitations are the minor medical intervention, the lack of validation and/or repeatability criteria of the standardized quality of life questionnaires.

Conclusion

Progress in medical and surgical approach to the disease are main options to change the disease natural history and definitely improve HS patients' quality of life. Besides, there are daily limitations that cosmetic types of intervention might face, such as the overall skin appearance, epilation measures, perspiration avoidance and type of dressing. Asking patients unveiled several unmet needs, which should be taken on charge by the physicians to improve the HS social acceptability, challenge isolation and depression, help patients to lose weight and perform sports activities, all issues which can further improve the disease management.

Acknowledgement

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List of abbreviations

HS: Hidradenitis Suppurativa.

Ethics

Data collected in this survey were anonymous and adhesion to the study on a voluntary basis, by opening the free access questionnaire on the HS patients' Association Inversa Onlus website, with the clearly stated intent of results divulgation to the community. Thus, no research ethics were transgressed.

Consent to publish

Patients were informed on the Inversa Onlus website of the survey aims, and agreed to divulgate the results to the scientific community. The free access page did not open the questionnaire without clicking the consent button.

Availability of data and materials

The free access to the original questionnaire on the *Inversa Onlus* website is no more available. It was supplied for a limited period (30 days), and then deactivated. Data have been analyzed as row numbers and percentage, shown on the figure text. The link to the original patients' submission has been delated to maintain patients' privacy.

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None.

Competing interest

The Authors have declared that no conflict of interest exists.

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