

## CLINICAL REPORT

## Psychosocial Impact of Hidradenitis Suppurativa: A Qualitative Study

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**Hidradenitis suppurativa influences patients' lives in many ways. It is therefore necessary to focus on the effects of the disease on daily life in order better to define patient-related outcomes in hidradenitis suppurativa studies. Interviews were conducted with 12 patients with hidradenitis suppurativa. Initial single interviews were followed by semi-structured and structured qualitative focus group interviews in order to improve the richness of the data and obtain in-depth understanding of the impact of the topics. Important topics were found to relate to aspects of interpersonal contact, especially in relation to smell and appearance, various emotional reactions, and feelings of lack of control. It was found that hidradenitis suppurativa has a great emotional impact on patients and promotes isolation due to fear of stigmatization. Shame and irritation are frequent and relate to smell, scars, itching and pain. Quality of life is adversely affected and professional support is needed. Key words: interview; quality of life; hidradenitis; smell; emotion; stigmatization.**

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Hidradenitis suppurativa (HS) is a chronic, recurrent, debilitating inflammation of the hair follicles, typically in the groin and armpits. It is scarring, creates sinus tracts and often produces a malodorous and recurrent discharge. The disease is often painful and the lesions can be itchy. HS is generally not a well-known disease and many non-dermatologist clinicians are unfamiliar with it.

It is estimated that HS affects 0.33–4% of the population in Europe (1, 2). Onset usually occurs immediately after puberty, but it may develop at any time during adolescence (3). It affects women more often than men (1). The aetiology of HS is unknown, but the pathogenesis involves inflammation of the hair follicles.

It is easy to imagine the psychosocial impact of the disease, and yet this has been the topic of only a few studies (4–8). To obtain an increased understanding of the psychosocial problems associated with HS and their contexts qualitative methods are of relevance. Because of their explorative nature qualitative methods can provide new points of view about a given problem (9).

Furthermore, an increased and specified understanding of topics suggested by quantitative surveys, such as the Dermatology Life Quality Index (DLQI) (10), may be obtained through interviews. Quantitative surveys based on DLQI show that HS has a significant effect on the quality of life (QoL) of patients with HS (4, 6, 7). Matusiak et al. (7) showed that HS has a large or extremely large effect on patients' QoL in nearly 60% of examined patients. Both Matusiak et al. (7) and von der Werth & Jemec (4) note that HS appears to cause greater impairment in QoL than do other dermatoses. The disease may therefore be expected to have considerable associated psychosocial problems. In order to provide a better understanding of the life situation of patients with HS it is therefore of urgent importance to specify and clarify these problems.

## MATERIALS AND METHODS

Patients with HS were recruited from the outpatient clinic at the Department of Dermatology, Roskilde Hospital. Patients were invited face-to-face, by letter or by telephone to participate in interviews. The interviews were performed with the same interviewer in all cases (SE). All the interviews were tape-recorded and transcribed verbatim.

By accepting the invitation to participate in the interviews the patients provided informed consent. In Denmark qualitative surveys do not legally require ethics committee approval.

A total of 12 patients participated in the interviews (9 females, 3 males); mean age 36 (age range 27–48) years. Table I shows the duration of HS, Hurley score and treatment of the participants during the past 2 years.

The interviews took place over a period of nearly 2 years, from June 2008 to March 2010. Initially seven patients participated in a single interview (4 females, 3 males). Four of the participants agreed to join the focus group interviews along with additional

Table I. Characteristics of participants with hidradenitis suppurativa in interviews

Sex/Age <sup>a</sup>	HS symptoms		
	Years	Hurley stage	Systemic treatment
M/27	6	II	No
M/29	>10	III	No
F/29	>10	III	Yes <sup>b</sup> (Surgery)
F/30	>10	II	Yes <sup>b</sup> (Surgery)
F/31	>10	II	No
F/32	>10	I	Yes (Surgery)
F/740	>10	III	Yes <sup>b</sup>
F/41	>10	II	No
F/42	>10	II	Yes <sup>b</sup> (Surgery)
F/43	>10	II	Yes
M/45	>10	III	Yes (Surgery)
F/48	>10	II	No

<sup>a</sup>years at interview. <sup>b</sup>Including TNF $\alpha$  blockers.

patients. At the first focus group interview three of the four patients accepted the invitation to participate, and two attended (1 female, 1 male). At the next interview 6 out of 8 accepted the invitation, and 5 attended (3 females, 2 males). At the third interview 5 out of 6 accepted, and 2 attended (1 female, 1 male). Finally, a focus group interview was performed with patients who had not been interviewed previously (3 females). Seven patients were invited, six agreed to participate, and one did not answer. Three were able to participate on the chosen date.

The interviews were established in accordance with qualitative methods founded on critical psychology, hermeneutics and phenomenology (11–13). The methods cover first-person perspectives on daily life, focus on the subjective possibilities of action, and explore the way the individual faces the hindrances and dilemmas that arise in varying degrees with, for example, a chronic disease such as HS. Through the recognition of psychological structures revealed by the individual's participation, motivation, reasoning and finding meaning in the context of the disease, the analysis of the interviews aims at identifying central topics of general relevance (9). General relevance is found because the individual will be referring to a context of structures developed by society.

Initially single interviews of 1–1.5 h duration were arranged. The interviews were open and explorative, but with a focus on the daily impact of HS. The patients were asked to report whether/how HS affected their daily life now, but also whether/how it had had an impact on their life at a younger age. Thus an insight into different age-related topics would be obtained.

Transcription of the single interviews was performed initially and, based on a primary analysis of statements given at the different interviews, topics that had a HS-specific importance were identified.

Next, focus group interviews of 3 h duration were arranged. At this level the interviews were semi-structured relating to the topics found earlier. Again, the interviews were transcribed, and through analysis a more detailed description and understanding of the impact of the topics was found. Communication in the focus group provided insight into the complexity of meaning and reasoning in relation to HS found in the single interviews. A final focus group interview was arranged with a structured interview-guide to verify/graduate the previous findings. The interview-guide was developed through analysis of the previous interviews arranging the provisional results in categories with subordinate questions.

In addition to identifying topics of relevance to patients with HS, the interviews may have had a therapeutic effect for the participants. For subjects who have a disease that can often be hidden, it may be of major importance and have a great influence on them to be able to share their problems with one or more persons in an interactive meeting.

## RESULTS

The interviews identified a number of topics relating to various aspects of interpersonal contact of both psychological and social origin; to various emotional factors and to factors relating to physical symptoms. An overview of the results is given in Table II.

The results are described under the following sub-headings:

### *Emotions and self-worth*

A natural variation in the degree of self-worth and social courage is found depending on the symptoms of HS. Patients feel unworthy and not lovable when they have large/many scars and ongoing boils. "You are kind of abnormal when you are walking around with scars everywhere.", "One feels unattractive, because it looks ugly and smells ugly."

Table II. Results of the analysis of patient interviews on the psychosocial impact of hidradenitis suppurativa (HS)

Main categories and subcategories
<i>Emotions and self-worth</i>
Depression. Sadness. Irritation. Worry. Helplessness. Dependency. A feeling of lack of control. Suicidal ideation.
<i>Taboo and stigmatization</i>
Feel impure. Shy. Smell. Scars. Isolation.
<i>Intimate relations</i>
To find a partner. In relationship. Sexuality.
<i>Cognition</i>
To have a diagnoses or a name of the disease. Acceptance of the disease.
<i>Communication</i>
To talk about the disease. Group meetings.
<i>Precautions</i>
Dressing. Gestures. Perfumes. Contagiousness. Tobacco. Weight. Sport.
<i>Economy and work</i>
Job. Colleagues. Sick leave. Cost of care.

Various emotional reactions to HS were reported. Irritation, anger and sadness are often experienced when lesions appear. Patients reason that the lesions look ugly, smell, appear quite frequently and are painful. Sadness and worry also occur when patients are unable to do their work because of HS, or if the disease is unaffected by the treatment provided.

Patients generally find that their QoL is reduced by HS. They recognize that the reason for the low QoL is multifactorial. It is not exclusively dependent on HS, but the disease is, however, a very important factor because it is so painful and uncontrollable.

The painful lesions often limit daily activities, such as dressing or moving around. This leads to a feeling of helplessness and dependency on other people during these periods. The aim of having control is challenged, and at times HS is found to have taken control of the patients' lives. At such times it is difficult for patients to make appointments even one week ahead due to the fact that the disease might worsen.

As flares can last for many days this easily results in depressive moods. One patient reports: "It lasted a fortnight; I was totally helpless. I could just hide under my duvet."

Periods of depression are recalled during the interviews, especially at a younger age (adolescence, young adulthood). One 31-year-old patient relates that her HS began at the age of 14 years. She became depressed, and over the following 9 years she had a chaotic life due to the psychosocial impact of HS. Her self-worth was low and limited her social interaction, e.g. she did not dare to date due to the disease. She misused drugs and alcohol and tried to commit suicide several times: "... a central reason was the boils, which caused an extremely low self-worth." This was corroborated by another patient who also admitted to low self-worth, alcohol abuse and suicidal ideation. A feeling of having lost important experiences in adolescence is apparent, followed by the recognition of being better prepared for having HS at an older age.

### *Taboo and stigmatization*

Recalling the age of 10–25 years the patients tend to view their lesions as a taboo. They report having avoided talking about their symptoms, even with their family. Consulting a

clinician for other reasons, they may have found the courage to talk about their HS once the forum for communication about health problems was successfully established.

The patients still find the symptoms very embarrassing and repulsive, feel themselves to be impure and feel shy about it. They are very much aware that the discharge is malodorous. During periods of heavy discharge they do not seek company, but remain isolated at home. They can be so focused on the risk of smell from their armpits that they keep their arms fixed in the hope that the smell will stay "inside" the armpit. This may result in shoulder pain. They also may feel that they can smell it all the time and they are constantly aware of whether other people sense the smell. However, they may also be in doubt as to whether they smell and depend on their relatives to say: "You smell – do you mind taking a bath". During periods when many lesions are present they bathe several times a day and feel the need to be able to change their clothes during the day.

Patients also feel embarrassed because they have visible scars, and they hide the affected areas by wearing long-sleeved blouses, trousers or long shorts. They fear peoples' reaction when they reveal the usually hidden parts of their body, e.g. in a sexual relationship or in a changing room. They fear that people will find them disgusting and therefore they modify their behaviour to prevent an unpleasant situation from occurring, e.g. by postponing bathing after sport until the majority of other people have finished.

Patients with small children may feel obliged to go swimming in public pools, but they experience self-consciousness when walking around in their swimsuits.

Imagination about other peoples' reactions to the disease can prevent patients from going out in public. The risk of smelling bad because of discharging lesions is an important factor, but the often unendurable pain and itching from developing lesions may also lead patients to cancel appointments. If committed to a social event, patients have to find ways to cover up the lesions and take pain-killers.

In addition to the symptoms of HS, patients generally experience a change in mood and extreme fatigue during flares. They are aware that it may be a reaction of relinquishment, but it often makes them choose to stay at home.

#### *Intimate relations*

Patients with a partner find comfort in the fact that they are in a relationship. In a new relationship it is nevertheless a great burden for many patients that they have scars and deformations. They are embarrassed by it, and are afraid to tell a new partner: "Now listen, I have this disease which is a kind of infection. It is not contagious, but it might prevent me from having sexual intercourse with you." Such a conversation obviously requires a certain degree of courage and self-worth. They avoid showing their skin to their partner if they have discharging lesions.

Some patients find it important to tell a partner about their disease before having bodily contact, while others find it natural only to answer questions when their scars are revealed to the partner. Among the interviewees some report that they are still living in a partnership, but their sexual life has stopped because of HS. A few patients report that they have had experiences of former partners who lost interest in them when the HS lesions appeared.

Patients generally look at dating as troublesome, because they find the situation with disgusting lesions too complicated and too difficult to explain, and this makes them push people away. "Usually, I have no problems talking with people, but in such situations I simply shut people off." A patient reports with regret that she has realized that "I am not going to marry anyone and in any case I am not going to have children".

#### *Cognition*

It appears to be important to have a diagnosis or to put a name to the disease. Newly diagnosed patients have previously not been told or understood that their symptoms in fact are due to a specific disease. They were all treated for years by clinicians who were apparently unaware of the diagnosis. Their lesions were treated as temporary symptoms and they had no explanation of repeated lesions, e.g. "Why should I visit five dermatologists before I got an explanation." The naming of the diagnosis represents an important change in their situation and is perceived as a great relief.

Patients are generally aware that the disease is chronic. They appear to accept the disease as long as it cannot be cured, but they find it difficult to be told: "You have got to learn to live with it." by some physicians.

#### *Communication*

There appears to be consensus among patients that ageing allows them to become more open about their disease. They would like to talk about their symptoms to relieve their feelings, but may be reluctant to share it with just anyone. They generally find it sufficient to talk with their relatives, e.g. giving an explanation of a change in mood or a refusal of intimacy. In questions about intimate, personal HS-related problems they may find it easier to talk with strangers than with their family. During the interviews the patients relate that they feel alone with their disease and would like the possibility to meet other people with HS or to contact people with HS on websites. There appears to be a need to find out how others manage and behave in daily life. Patients are anxious to know that they are not alone in their experiences of the disease and they are aware that some aspects of HS can only be revealed during personal contact. Planning the focus group interviews thus showed that patients in general are very interested in communication with other patients about their disease, but hesitant to commit. Only two patients out of 12 did not want to participate in a focus group and only one of these because it was felt to be too intrusive, and it may be speculated that the sudden cancellations reflect a similar psychological mechanism.

#### *Precautions*

A continuous consideration for patients is how to dress. Black or dark-coloured, loose-fitting clothes, perhaps with an old T-shirt underneath, are preferred when the disease is active. Women report that they wear stockings or leggings to keep the bandages in place and if they wear a skirt they wear short trousers underneath. Patients generally try to hide their scars, although overcoming fears can provide a sense of accomplishment. One patient was encouraged by her husband to wear a sleeveless top, and spent a difficult day self-consciously agonizing about it, only to be rewarded with a feeling of triumph after having tried it.

On the beach patients prefer to hide under shorts and T-shirts with short sleeves. Particular problems are encountered by patients who have to wear white uniforms at work who fear spots from lesions appearing on their clothes. Many gestures are hindered because of the awareness of possible revelation of the scars.

The risk of smell results in the use of perfumes. A male patient says: "I put on perfume every day and even a bit more than I ought to because I hope to camouflage the smell."

It is difficult to participate in a variety of sports because the lesions can make movement very painful. In addition, sweating may cause stinging.

None of the interviewees reported fearing that their disease is contagious. One patient reports that years ago she was told by her practitioner that her lesions were contagious and that she had lived with this conviction until she recently received her HS diagnosis. Until then she had avoided public swimming pools and taken other precautions.

Patients are aware of advice to stop smoking and to lose weight. Generally they report that they intend to do so, but one patient reports that she finds it very difficult to have to deal with these issues in addition to the problems of having the disease. She considers that it is too easy to recommend these kind of changes and, rather than the provision of general guidelines, she would prefer an understanding of the difficulties caused by the disease.

#### *Economy and work*

An important issue for patients is the cost of the bandages and towels in addition to the prescribed medicine. Also, there is a risk of low income due to repeated sick leave and/or dismissal. There is a wish to avoid sick leave, and many patients succeed in doing so in spite of soreness and pain. Nevertheless, it seems to be rather common to take sick leave because of HS. One patient estimates that she is on sick leave for a fortnight every second month due to HS. In general, the disease influences ability to work full-time. A possible solution is to work part-time and apply for support from social services. If the disease is very serious patients can request a flexible working arrangement with public support, which gives them the possibility of attending work to the degree that the disease permits.

The type of work the patient is doing may be of importance depending on the localization of the lesions. A job in which the patient has to stand or walk may be preferred because lesions between the buttocks and on the genital area make sitting difficult. Another possibility is a job with the flexibility to work at home during periods with painful lesions. Patients generally find it of relevance that their colleagues know about their symptoms, in order to prepare for and explain troublesome situations where assistance may be necessary (for example, when lifting during flares of axillary disease) or emotional reactions, changes in mood, etc. It may also help them to explain the different patterns of sick leave.

## DISCUSSION

Patients suffer in both their employment and their leisure time. The high impact of HS on employment and finances has been described previously (7, 8, 14). Matusiak et al. (7) found that 58.1% of 30 employed and professionally

active patients had work absence. In addition, the duration and frequency of work absence were high and 10% were dismissed. Ramasastry et al. (14) illustrates the problems with a HS patient who was forced to leave his job and was deserted by his family because of malodorous discharge. In further agreement with this, Jemec et al. (8) found that patients with HS have significantly higher levels of absence from work than the healthy population. The present study supplements this with personalized examples of frustrations related to the impact of HS on employment.

Based on the recall of the interviewees it was found that younger people in particular are affected because of their efforts towards identity creation. The combination may explain reported reactions, such as alcohol abuse, suicidal ideation or frank suicide attempts in adolescence. Patients react emotionally in various ways. Irritation, anger, sadness, worry and depression are a result of pain, itching, smell and scars, but also because the HS appear without control and may flare randomly. Patients want to have a diagnosis of their symptoms and wish to understand the disease. Through a diagnosis the prerequisites for a cognitive attitude are obtained, giving the patients the possibility either to identify with the disease or to distance themselves emotionally.

Patients generally do not perceive themselves to have any influence on their disease and the variety of symptoms. Patient empowerment through self-treatment may therefore be of particular interest to this group. Data suggest that tobacco abstinence (15) and weight reduction may be beneficial (2, 16), but the pursuit of these goals adds stress and may limit coping.

Unfortunately, the increased idolization of a perfectly trimmed body, e.g. by cosmetic surgery, predominates in society in general (17). This may negatively affect the self-worth of patients with HS, in addition to having a major influence in people with only minor deviations from the ideal. Several dermatological studies have shown that patients with visible skin diseases are influenced by fear of stigmatization and behave in a variety of ways in order to prevent stigmatization (18). Patients with more severe disease (Hurley stage II or III) deviate significantly from the published ideal, and although they are fortunate in that normally they can hide their lesions, they appear to be deeply influenced by the risk of accidentally revealing their scars or smelling bad. The fear of stigmatization and exclusion from the group is a phenomenon that uniformly affects patients with HS.

Goffman (19) distinguishes two ways of experiencing stigma: as discredited or as discreditable. He describes a discredited individual as one who shows visible signs of being different, and a discreditable individual with still-invisible signs of stigma. Schmid-Ott et al. (20) point to a difference in the experience of stigmatization. If the lesions are visible the patients experience a higher level of stigmatization compared with those with invisible lesions. Patients with HS fall into the gap between visible/invisible or discredited/discreditable. Their disease is invisible as it can be covered by clothes, but smell may reveal their secret. Thus the group of patients with HS presents a fear of stigmatization relating to revealing the normally hidden scars and an involuntary release of bad smell. The fear influences their appearance in society in ways that result in HS-specific precautions, e.g. perfume, bandages, spare clothes, isolation, etc.

The degree of impairment in QoL at first seems to relate to age. Memories of adolescence among the interviewees show that HS is perceived as hindering the possibility to act in the same way as peers and this may be of high importance for self-worth and QoL. Depending on the personality of the HS patient it may result in either isolation or confrontation, a negative or positive attitude in facing hindrances (21, 22).

Based on the interviews the tendency appears to be that the majority of young patients with HS feel depressed, unworthy and unlovable, while older patients with HS to some extent find a way of "controlling" their conditions, e.g. by taking pain-killers, wearing loose-fitting, dark-coloured clothes and tight bandages, being fit and healthy, etc. It would appear that the development of a successful coping mechanism is possible. Nevertheless, surveys show a high frequency of depression among patients with HS. Matusiak et al. (6) show that 21% of patients with HS have co-existence of depression (Beck Depression Inventory (BDI)  $\geq 10$ ), with a mean age of  $36.18 \pm 8.83$  years at disease onset. Obviously this was not found to the same degree in the interviews, as there was limited contact with patients who had actual depression or ongoing malodorous lesions. Patients with depression may naturally have been reluctant to participate due to their current situation.

Motivation to be in a relationship is powerful and is of high importance for patients with HS, as for most people. Few patients report that their partners find the lesions unacceptable, and the overall impression is that partners accept the condition, even during long periods without sexual activity.

Communication about the disease in general is seen by patients to be highly relevant. In the interviews the patients with HS express an interest in meeting virtually or in group meetings. They appreciate the possibility to share even intimate information with other patients with HS. The interviewees do not have the same interest in sharing their troubles with non-HS patients. Through the interviews it was clearly seen that the patients felt the disease to be taboo and had avoided talking about their suffering with others because they felt themselves to be impure. Joachim & Acorn (18) point to the uncertainty among patients with chronic illnesses and conditions about how to manage information about their disease. The degree of information patients wish to share depends on their willingness to risk a negative reaction from others. People may react with empathetic support, but also by distancing themselves, and the patient risks feeling rejected, stigmatized and feeling a lack of control.

It is therefore suggested that patients with HS may benefit from courses arranged especially for groups of patients with HS with the aim of giving some relief from socially induced demands. These groups can serve both as support groups and as backing groups for an individual's participation in society. A focus on coping behaviours to hide or compensate for scars (23) and smell would also be of relevance for patients with HS. Finally, all patients with HS should be introduced to the Hidradenitis Suppurativa Foundation ([www.hs-foundation.org](http://www.hs-foundation.org)), which provides a valuable forum for patients.

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