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SHORT REPORT

Stigmatization, a social perception which may have a debilitating impact on hidradenitis suppurativa patients: an observational study

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Abstract

Hidradenitis suppurativa (HS) is a debilitating disease and patients are prone to feelings of stigmatization. In our cohort, we assessed how feelings of stigmatization may relate to patient quality of life (QOL), depression, and social anxiety. Participants completed the Dermatology Life Quality Index (DLQI) to assess QOL, Patient Health Questionnaire 9 (PHQ-9) to assess depression, the Brief Fear of Negative Evaluation (BFNE) to assess social anxiety, and an adapted version of the Feelings of Stigmatization (FoS) to assess stigmatization. The FoS also correlated with DLQI ($R=0.68$), PHQ-9 ($R=0.42$), and BFNE ($R=0.52$). Participants with greater FoS were also more likely to have worse QOL (18.1), higher levels of depression (11.1), and higher social anxiety (30.1), as compared to those with less FoS (6.7, $P<0.001$; 4.9, $P<0.001$; 23.2, $P<0.001$, respectively). HS is a chronic disease with no definitive treatment. Effective screening protocols, coupled with pharmacological and nonpharmacological interventions, may help patients with HS's psychosocial burden.

Keywords Depression · Hidradenitis suppurativa · Quality of life · Social anxiety · Stigmatization

Introduction

Hidradenitis suppurativa (HS) is a debilitating skin disease that can negatively impact patient quality of life (QOL), even in mild disease [1, 2]. Stigmatization, defined as the awareness of devaluation, discrediting, or social disapproval based on a physical mark or attribute, can cause patient psychosocial burden secondary to distorted self and social image [3]. The past studies assessing feelings of stigmatization in HS are limited to qualitative studies and few quantitative reports. In the past qualitative studies, patients have stated experiencing stigmatization and fear from visible signs of their disease, specifically referencing visible scars, sinus tracts, and abscesses [1, 4, 5]. Moreover, even signs typically covered by clothing, such as drainage and odor, can lead to patient shame and isolation due to fears of negative reaction [1, 4]. Furthermore, disease flares can exacerbate feelings of stigmatization, causing patients to conceal their signs and symptoms of disease due to fear of stigmatization [6, 7].

Although there are limited quantitative studies assessing feelings of stigmatization using an objective measure, feelings of stigmatization have been associated to be proportionately dependent on the clinical stage and location of the disease [4]. Moreover, the association between stigmatization secondary to HS and its relationship to psychiatric comorbidities and burden of HS is limited. In our HS patient cohort, we assessed stigmatization and its relationship to patient quality of life (QOL), depression, and social anxiety using objective tools.

Methods

Our research group approached total 153 participants ($n=30$ clinic; $n=123$ mail) between June and September 2018 who had received a clinical diagnosis of HS (ICD-10 code: L73.2) from the Atrium Health Wake Forest Baptist Dermatology clinic within the past five years after IRB approval

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was obtained [2]. Total 67 responses (response rate 44%) were received (clinic: $n = 27$, RR 90%; mail: $n = 40$, RR 33%).

Participants completed the Dermatology Life Quality Index (DLQI), to assess for skin-related QOL, Patient Health Questionnaire 9 (PHQ-9), to assess for depression, and the Brief Fear of Negative Evaluation (BFNE), to assess for social anxiety. Increasing scores on the DLQI, PHQ-9, and BFNE correlate with worse quality of life, increasing levels of depression, and social anxiety, respectively. Disease severity was assessed using a validated self-assessment tool to measure Hurley Stage [8]. The Hurley Staging System is an objective measure of HS severity and separates patients into stages 1–3. The presence of sinus tracts and scarring, level of diffuse or interconnected involvement, and abscess formation is used to assess stage [8].

Participants completed an adapted version of the Feelings of Stigmatization (FoS) survey to measure stigmatization. The Feelings of Stigmatization survey is a 33-item questionnaire, originally designed for patients with psoriasis, that measures six domains of stigmatization: feelings of being flawed, anticipation of rejection, guilt and shame, sensitivity of others, secretiveness, and positive attitudes [9]. Our adapted version of the survey contained 31 of the original 33 questions and excluded 2 psoriasis specific questions [9]. Scores can range from 0 (strongly disagree) to 5 (strongly agree) and higher scores correlate with greater feelings of stigmatization (range 0–minimum stigmatization to 155–maximum stigmatization) [9]. Respondents were divided into two groups based on the median FoS (72): high stigma (≥ 72) and low stigma (< 72).

Differences in group comparisons by mean score were analyzed using *Student's t test*. Simple linear regression was used to analyze associations between the survey tools and relationships were analyzed based on the Spearman's coefficients of rank correlation. All data were analyzed using the SAS Software 9.4.

Results

Respondents were mean age 39, 57% were African American (AA), and 90% were females, as compared to nonrespondents mean age 36, 38% AA, and 80% females. The average stigma score was 74 and the median score was 72. The FoS correlated weakly with PHQ-9 ($r = 0.42$, $F = 13.2$, $P < 0.001$), and moderately with DLQI ($r = 0.68$, $F = 55.2$, $P < 0.0001$) and BFNE ($r = 0.51$, $F = 21.6$, $P < 0.001$).

Respondents with low stigma had a lower average DLQI (6.7), as compared to respondents with high stigma (18.1, $P < 0.0001$) (Table 1). Respondents with low stigma also had a lower average PHQ-9 (4.9), compared to respondents with high stigma (11.1, $P < 0.001$). Respondents with low stigma had a lower average BFNE (23.2), as compared to those with higher stigma (30.1, $P < 0.001$).

There was no difference by disease severity (mean FoS: Hurley Stage I-69, Stage II-77, Stage III-76; $P = 0.52$).

Table 1 Feelings of stigmatization and quality of life in hidradenitis patients

DLQI questions	High stigma ($n = 32$)	Low stigma ($n = 35$)
Over the last week, how **itchy, sore, painful, or stinging** has your skin been?	2.0	1.5*
Over the last week, how **embarrassed or self-conscious** have you been because of your skin?	2.0	0.8**
Over the last week, how much has your skin interfered with you going **shopping** or looking after your **home or garden**?	1.4	0.5**
Over the last week, how much has your skin influenced the **clothes** you wear?	1.2	2.4**
Over the last week, how much has your skin affected **social or leisure activities**?	2.0	0.5**
Over the last week, how much has your skin made it difficult for you to do any **sport**?	2.0	0.5**
Over the last week, how much has your skin prevented you from **working or studying**?	1.7	0.5**
Over the last week, how much has your skin created problems with your **partner** or any of your **close friends or relatives**?	1.6	0.3**
Over the last week, how much has your skin caused any **sexual difficulties**?	1.8	0.5**
Over the last week, how much of a problem has the **treatment** of your skin been for example making your home messy or by taking up time?	1.3	0.5**

Sum and individual Dermatology Life Quality Index scores stratified based on the feelings of stigmatization

DLQI Dermatology Life Quality Index

$P < 0.05$*, $P < 0.001$**

Discussion

There is limited literature on how feelings of stigmatization may affect patient life and comorbidities. In our cohort, most participants felt stigmatized (per mean FoS). In contrary to the past reports, in our cohort even participants with mild HS (per Hurley Stage) experienced feelings of stigmatization, suggesting even a few abscesses (i.e. Hurley Stage I), and their resulting malodor and scars, may lead to feelings of stigmatization [1, 4]. Participants who felt more stigmatized were also more likely to experience worse QOL in all aspects (per sum and individual DLQI), as compared to participants with less feelings of stigmatization. Moreover, participants with greater feelings of stigmatization also had more depression and social anxiety, suggesting increased feelings of stigmatization increased the risk of these psychological comorbidities in our cohort.

HS is stigmatizing chronic disease with no definitive treatment. Efforts to increase public awareness regarding the debilitating physiological and psychological nature of HS may help patients cope with their disease and feelings of stigmatization, however such efforts may take many years to put into action [1]. Currently, most dermatologists and other healthcare providers who treat HS lack psychiatric training [10]. Effective screening protocols, coupled with pharmacological and nonpharmacological interventions may help patients cope with the psychosocial burden of HS [9, 10]. In past qualitative studies, HS patients have self-reported seeking and benefiting from support through friends, partners, family, and online groups to cope with feelings of stigmatization [6]. According to the self-categorization and social identity theories, patients may try to view their ingroup in a favorable fashion in order to maintain self-esteem [11]. However, patients with HS who feel stigmatized may have low self-worth and may struggle to create a favorable view of the ingroup [12]. Thus, establishing a collective identity through HS-centered support groups may help increase patient self-worth [12]. Moreover, patients who have participated in HS specific social support groups also have reported better QOL, as compared to HS patients who have not [13]. Online support groups may also provide an effective and accessible alternative, especially considering the ongoing COVID-19 pandemic [13, 14].

Although our study was limited by our response rate, demographics of nonrespondents were similar and effect sizes were large enough to find statistically significant differences in survey tool scores. Furthermore, although the FoS is a validated objective measure of stigmatization, it was originally intended for patients with psoriasis.

HS is a complex disease, and a multidisciplinary patient-centered focus on the treatment of both the physical and psychosocial aspects of HS with pharmacological and behavioral interventions may help decrease HS burden.

Conclusions

HS is a debilitating complex disease, and, in our cohort, most participants felt stigmatized, regardless of disease severity. Participants who felt more stigmatized were also more likely to have worse QOL, more social anxiety, and depression. A multidisciplinary patient-centered focus on the treatment of both physical and psychosocial aspects of HS may help decrease HS burden.

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Author contributions RS, KAK, SRF, and ROP were responsible for conceptualization and all authors developed and designed methodology. RS, AS, SRF, and ROP performed the investigation. RS and KAK performed the formal analysis. RS and KAK wrote the main manuscript text. AS, SRF, and ROP reviewed and edited the manuscript. SRF and ROP supervised the manuscript and were involved in project administration.

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Declarations

Conflict of interest Feldman has received research, speaking and/or consulting support from a variety of companies including Galderma, GSK/Stiefel, Almirall, Leo Pharma, Baxter, Boeringer Ingelheim, Mylan, Celgene, Pfizer, Valeant, Taro, Abbvie, Cosmederm, Anacor, Astellas, Janssen, Lilly, Merck, Merz, Novartis, Regeneron, Sanofi, Novan, Parion, Qurient, National Biological Corporation, Caremark, Advance Medical, Sun Pharma, Suncare Research, Informa, UpToDate and National Psoriasis Foundation. He is founder and majority owner of www.DrScore.com and founder and part owner of Causa Research, a company dedicated to enhancing patients' adherence to treatment. Pichardo has worked in the advisory board for Novartis. Singh, Kelly, and Senthilnathan have no conflicts to disclose.

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