The psychosocial burden of hidradenitis suppurativa in Singapore



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Background: Hidradenitis suppurativa (HS) is a chronic debilitating inflammatory skin disorder known to result in significant psychological symptoms and impaired quality of life. However, most of these studies are limited to western countries, with limited data from other sociocultural regions.

Objective: To understand the psychosocial burden of HS in the Asian context, by exploring the correlation between objective disease measures with psychosocial health and work productivity.

Methods: A prospective single-center questionnaire study was conducted. A total of 45 patients with HS completed a questionnaire and examination by a dermatologist.

Results: Higher objective disease severity scores (Hurley, physician global assessment, International Hidradenitis Suppurative Severity, and modified Sartorius) correlated with poorer quality of life (Dermatology Life Quality Index and Patient Global Assessment), increased anxiety and depression (hospital anxiety and depression scale) and at-work productivity loss. There was no significant correlation between objective disease severity and other domains Work productivity and activity impairment score or self-esteem (Rosenburg Self-Esteem Scale).

Limitations: The main limitation of our study is the small sample size, assessment at a single time point, and lack of control cohort.

Conclusion: Our findings demonstrate the impact of HS on a patient's psychosocial well-being and emphasize the importance of treating patients from a holistic standpoint. (JAAD Int 2023;10:89-94.)

Key words: acne inversa; anxiety; depression; disease burden; hidradenitis suppurativa; psychosocial; psychological impact; quality of life; work productivity.

INTRODUCTION

Hidradenitis suppurativa (HS) is a chronic debilitating inflammatory skin disorder that often leads to significant psychological symptoms and impaired quality of life (QoL). HS affects about 1% of the population, with prevalence rates ranging from 0.00033% to 4.1%.¹ The disfiguring lesions, foulsmelling discharge, scarring, and pain can result in significant QoL impairment that exceeds other dermatoses such as psoriasis, atopic dermatitis, and acne vulgaris. The partial and transient efficacy of many HS treatments account for the ongoing

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physical, emotional, social and economic impairment, and the association with significant psychological distress and psychiatric comorbidity.²

In this study, we aim to further the understanding of the psychosocial burden of HS, by exploring how demographic factors and objective disease measures correlate with the cognitive and emotional state and

CAPSULE SUMMARY

Higher objective disease severity and

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productivity loss in HS patients.

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how these influence school and work productivity. We know that in Asian populations, there are biological and phenotypic disease differences³⁻⁵ as well as cultural and socioeconomic variations,⁶ and thus aim to provide further understanding in an Asian context that contrasts with the large majority of studies conducted in Western populations.

MATERIALS AND METHODS

We conducted a prospective single-center questionnaire study in the Division of Dermatology, National University Hospital, an academic tertiary center in Singapore. Patients with dermatologist confirmed diagnosis of HS were invited to participate and complete a questionnaire which assessed the following: demographics, pain (visual analog scale [VAS] score⁷), QoL impairment (Dermatology Life Quality Index [DLQI],⁸ patient global assessment of QoL impairment [PtGA]⁹), anxiety and depression (hospital anxiety and depression Scale (HADS)),¹⁰ self-esteem (Rosenburg self-esteem scale),¹¹ and work impairment (Work Productivity and Activity Impairment Questionnaire (WPAI): Specific Health Problem¹²). Domains assessed in WPAI include absenteeism, presenteeism, overall work impairment and activity impairment due to HS. Questions pertaining to school absenteeism were also added.

All patients were physically examined and objective disease severity was graded with the following: Hurley score,¹³ physician global assessment (PGA),¹⁴ modified Sartorius¹⁵ and International HS Severity Score¹⁶ score. The primary caregiver or closest family member was also invited to fill the family dermatology life quality index to assess the impact of HS on the family.

Descriptive statistics were presented as percentages, means, or medians. Spearman rank correlation was used to assess the correlation between demographic and disease characteristics with patient reported outcome measures.

RESULTS

Forty-five patients (20 females, 25 males) with HS were recruited between January 25, 2021, and September 20, 2021. The median age was 32 (interquartile range [IQR], 23-41) years old and 4 participants were under 18 years of age. Thirty-four were adults of working age and 11 were school going.

Most patients had mild disease with 27/45 having stage 1 Hurley disease. Associated comorbidities included hypertension (n = 7), hyperlipidemia (n = 6), diabetes mellitus (n = 6), and depression (n = 1) (Table I).

Pain was a common symptom (27 out of 45 participants reported pain) although the median VAS pain score was only 2/10 (IQR, 0-5). Thirteen of 45

and 7/45 fulfilled the HADS scoring criteria of depression and anxiety, respectively. Nine of 45 met the scoring criteria for low self-esteem.

There was an unemployment rate of 17.6% (6 out of 34 adults unemployed). Impact of HS on work productivity was assessed by the WPAI score. Further interpretation of WPAI is shown in Fig 1.

Of 11 schooling patients, 3 reported missing at least 1 day of school over the past 8 weeks due to HS. Two reported an inability to attend extracurricular activities due to reasons including physical pain, itch, and limitations in movement. Interpersonal relationships were affected by HS in 2 schooling patients due to self-consciousness/embarrassment from foul smelling discharge and inability to wear desired clothing, physical discomfort such as pain, and insufficient time due to the need for dressing change and clinic visits.

Spearman correlation tests found that higher physician-graded objective disease severity (Hurley, PGA, and HS Severity Score) correlated with poorer QoL (higher DLQI and PtGA, correlation coefficients between 0.43-0.67, *P* values < .01) and increased anxiety and depression (higher HADS, correlation coefficients 0.41-0.47, P value < .01) (Fig 1, Supplementary Table 1, available at Mendeley https://data.mendeley.com/datasets/x7978y7n77). There was no significant correlation between physician-graded objective disease severity and self-esteem. No correlation was found between modified Sartorius and patient reported scores. In terms of work impairment, higher PGA was found to

| DLQI: | Dermatology Life Quality Index |
|--------|--|
| FDLQI: | family dermatology life quality index |
| HADS: | hospital anxiety and depression Scale |
| HS: | hidradenitis suppurativa |
| IQR: | interquartile range |
| PĞA: | physician global assessment |
| PtGA: | patient global assessment |
| RSES: | Rosenburg self-esteem scale |
| VAS: | visual analog scale |
| WPAI: | Work Productivity and Activity Impair- |
| | ment Questionnaire |

be correlated with greater impaired productivity atwork productivity. There was no significant correlation between other physician-graded severity scores and other domains of WPAI (hours of work missed, overall work productivity loss and inability to do regular activities).

Higher VAS pain scores were found to be significantly associated with higher at-work productivity loss (correlation coefficient, 0.39; P < .05), poorer QoL (higher DLQI (correlation coefficient, 0.69; P < .01), PtGA (correlation coefficient 0.74, P < .01)), anxiety and depression (higher HADS (correlation coefficient 0.62, P < .01)) (Fig 1, Supplementary Table 1).

There was a poor and statistically non-significant correlation between self-esteem and physiciangraded objective disease severity measures (correlation coefficients between -0.12 and -0.23). However there was a significant correlation between poorer self-esteem and other patient reported outcomes, such as QoL (DLQI (correlation coefficient -0.30, P = 0.042), PtGA (correlation coefficient, -0.30, P = .047)) and anxiety/depression (HADS correlation coefficient, -0.37, P = .013).

With regards to disease sites, axillary and inguinal involvements were significantly correlated with greater VAS pain scores and inguinal, gluteal, and suprapubic involvements were associated with poorer QoL. Additionally, inguinal and gluteal involvement was correlated with anxiety/ depression.(Fig 1, Supplementary Table 1).

Seven family members were also recruited (5 parents, 1 spouse, and 1 sibling). Those with personal history of HS were excluded. Patients' age ranged from 17 to 38. The FLDQI ranged from 0 to 16 with a median of 3 (IQR, 2-8). Of the 7 respondents, 6 described some degree of impairment in their QoL. Three described small effect on their QoL (score, 2-5), 2 described moderate effect on their QoL (score, 6-10), and 1 had very large effect on QoL

Table I. Demographic and DescriptiveCharacteristics of Participants

| | N (%), all respondents (N = 45) |
|--|---------------------------------------|
| Age, Median (IQR) | 32 (23-41) |
| Gender, n (%) | |
| Female | 20 (44.4%) |
| Male | 25 (55.6%) |
| Race, <i>n</i> (%) | |
| Chinese | 20 (44.4%) |
| Malay | 9 (20%) |
| Indian | 15 (33.3%) |
| Others | 1 (2.2%) |
| BMI, n (%) | |
| Underweight (<18.5) | 0 (0%) |
| Normal (18.5-24.9) | 10 (22.2%) |
| Overweight (25-29.9) | 15 (33.3%) |
| Obese (>30) | 20 (44.4%) |
| Family history of HS, n (%) | - () |
| Yes | 6 (13.3%) |
| No | 39 (86.7%) |
| Comorbidities, n (%) | |
| Hypertension | 7 (15.6%) |
| Hyperlipidemia | 6 (13.3%) |
| Diabetes mellitus | 6 (13.3%) |
| Inflammatory bowel disease | 0 (0%) |
| Arthritis | 0 (0%) |
| Other neuchistric condition | 1 (2.2%) |
| Other psychiatric condition | 0 (0%) |
| Age of disease, mean (SD) | |
| Age at diagnosis | 21.8 (10.5) |
| Age at diagnosis | 27.9 (11.0) |
| 1 | 27 (60.0%) |
| 7 | 27 (00.0%) |
| 2 | 8 (17.8%) |
| Active disease location n (%) | 0 (17.070) |
| | 24 (53 3%) |
| Inquinal | 13 (28.9%) |
| Gluteal | 11 (20.5%) |
| Suprapubic/lower abdomen | 8 (17.8%) |
| Patient reported outcome measures | 0 (17.070) |
| Median (IOB) | |
| VAS pain maximum score 10 | 2 (0-5) |
| DLOL maximum score 30 | 2 (0 5) 4 (1-9) |
| PtGA maximum score 4 | 1 (0-2) |
| HADs- total, maximum score 42 | 6 (2-15) |
| HADs-anxiety, maximum score 21 | 4 (1.5-9) |
| HADs-depression, maximum score | 3 (0.5-6) |
| 21 | 5 (0.5 0) |
| Rosenburg self-esteem, maximum | 19 (16-23) |
| SCOTE SU More Droductivity and Activity | N - 29 |
| impairment (MDAI) Question as | N = 28 |
| response, Mean (SD) | (empioyea) |

Continued

| | N (%), all respondents (N = 45) |
|--|---------------------------------------|
| Q1 During the past 7 d, how many hours did you miss from work because of HS? | 0.54 (2.01) |
| Q2 During the past 7 d, how many hours did you actually work? | 41.18 (13.41) |
| Q3 During the past 7 d, how much did HS affect your productivity while you were working? | 1.43 (2.20) |
| Q4 During the past 7 d, how much did HS affect your ability to do regular activities? | 2.29 (3.04) |

BMI, Body mass index; *DLQI*, Dermatology Life Quality Index; *FDLQI*, family dermatology life quality index; *HADS*, hospital anxiety and depression Scale; *HS*, hidradenitis suppurativa; *IQR*, interquartile range; *PGA*, physician global assessment of disease severity; *PtGA*, patient global assessment of quality of life impairment; *RSES*, Rosenburg self-esteem scale; *SD*, standard deviation; *VAS*, visual analog scale; *WPAI*, Work Productivity and Activity Impairment Questionnaire.

(score, 11-20). The most significantly affected item reported was emotional distress experienced (1 point). Other high scoring items were impaired physical well-being (0.57 point), disrupted leisure activities (0.57 point), and extra housework (0.57 point). The low number of caregivers; however, limit the analyses that can be performed.

DISCUSSION

In this study, we found that higher physiciangraded objective disease severity was associated with poorer patient reported outcome measures such as pain, QoL, anxiety, and depression. In turn, higher pain scores were associated with work productivity loss, poorer QoL, anxiety, and depression. Interestingly, self-esteem was not correlated with physician-graded objective disease measures but with patient reported cognitive and emotional measures such as anxiety and depression, as well as QoL impairment. Correlation between different patient reported subjective outcomes were also stronger than those with physician reported objective outcomes.

The positive correlation between objective disease severity and DLQI is consistent with the results of previous studies, where patients with more severe disease reported worse QoL scores. Fabbrocini et al recruited 308 patients in a multicenter prospective study and found that patients with more severe disease reported worse QoL as captured by HIDRAdisk total scores.¹⁷ Krajewski et al's¹⁸ cohort of 1795 German patients had similar findings with positive correlation among QoL impairment, pain, and HS severity. A Japanese questionnaire based study similarly found positive correlation between disease severity (PGA, modified Sartorius score, and Hurley stage) and DLQI.¹⁹ No correlation was reported between disease severity and the components of social functioning, role-emotional or mental health of the Short Form-36 health survey version 2 QoL scale was performed in this study.

Reports from Western countries indicated that female patients with HS have greater impairment of QOL with higher DLQI, but this was neither seen in the Japanese nor in our study. Of note, it is important to highlight that most of the patients in our study had mild HS with 22% having no active disease at the time of recruitment. This explains why the DLQI in our population (median 4) is lower than other studies, where the DLQI ranges from 10 to 12. This also suggests that the other measures of psychosocial burden of disease in cohorts with more severe disease are potentially greater than herein reported.

Studies have shown the impact of HS on work productivity. Matsusiak et al²⁰ found that HS caused absenteeism in 58.1% of patients. A recent Dutch study further evaluated HS-related factors and work impairment. They found statistically significant correlation between patient-reported scores (pain, DLQI, and EuroQol-5D score) with presenteeism (*P* values < .001, .009, and < .001, respectively) as well as at work productivity loss (*P* values < .001, .005, and < .001, respectively).²¹

Although objective disease correlates well with many QoL outcomes, there is a still a discordance between physician-graded objective severity and patient's subjective symptom burden, and selfperception of the disease.²² Our study shows the lack of correlation between objective disease severity and low self-esteem. Two cross-sectional studies comparing a group of HS patients with a control group found lower self-esteem scores in HS patients $(19.5 \text{ vs } 22, P = .019)^{23}$ and $(19.91 \pm 1.79 \text{ vs})$ 19.77 ± 2.53 , P = .008).²⁴ In our study, low selfesteem (Rosenburg self-esteem scale score of <15) was found in 20% (9 out of 45) of our patients. One of the above studies found that the impact on selfesteem was more strictly related to the negative perception of body image, malodorous discharge, and location of lesions in exposed skin areas rather than the severity of the condition.²⁴ The negative perception of body image may mirror the findings of increased anxiety and depression in our patients with poorer self-esteem. Differences in a patient's cognitive appraisal, resilience and coping, as well as underlying psychological illness may result in a



Fig 1. Spearman correlation matrix and heat map of demographics and patient reported outcome measures in hidradenitis suppurativa. *BMI*, Body mass index; *DLQI*, Dermatology Life Quality Index; *FDLQI*, family dermatology life quality index; *HADS*, hospital anxiety and depression Scale; *PGA*, physician global assessment; *PtGA*, patient global assessment; *RSES*, Rosenburg self-esteem scale; *VAS*, visual analog scale. Work Productivity and Activity Impairment Questionnaire included the domains. OC1, absenteeism, mean % work time missed due to HS; OC2, presenteeism, mean % productivity loss at work; OC3, overall work impairment due to HS, mean % overall work productivity loss due to HS; OC4, activity impairment due to HS, mean % productivity loss in regular activities due to HS.

symptom burden that is disproportionate to the objective disease state. Addressing the symptoms of pain, as well as the cognitive and psychosocial aspects in tandem with biomedical therapeutics are important in improving patient reported outcomes without incurring excess health care cost and drug toxicity.

QoL in cohabitants of patients with HS was independently studied in 4 studies from Poland, Italy, Spain, and the USA using the Family Dermatology Life Quality Index (fDLQI). These studies consistently showed positive correlation between fDLQI and patient's DLQI and some of them also showed positive correlation between fDLQI and disease severity as measured by Hurley. We managed to recruit only 7 carers in our cohort of 45 patients, and thus numbers were not significant enough to run any statistical tests. However, we aim to further extend our study in the future by recruiting more carers to better assess the impact of HS on patient's carers.

Study limitations include a small sample size, and in particular, the lack of sufficient responses from family members of patients with HS that limited our ability to assess the impact of HS on family members, assessment at a single time point, and lack of a control cohort.

CONCLUSIONS

In conclusion, our findings show the importance of treating patients from a holistic standpoint that encompasses physical, emotional, and functional symptom management rather than focusing only on physician-graded objective disease state and severity. Given the proportion with impairment in QoL and daily activities, we recommend making QOL measurements a part of the standard assessment in management of HS patients, and to actively screen for symptoms of anxiety/depression, low self-esteem, and absenteeism from work or school.

Conflicts of interest None disclosed.

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