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## International Journal of Women's Dermatology



Original Research

Quality of life and sexual health in patients with hidradenitis suppurativa<sup>☆,☆☆</sup>A. Alavi, MD, MSc<sup>a,f,\*</sup>, D. Farzanfar, BArchSc, HBSc<sup>b</sup>, T. Rogalska, MD, MSc<sup>c</sup>, M.A. Lowes, MBBS, PhD<sup>d</sup>, S. Chavoshi, MA, PhD(c)<sup>e</sup><sup>a</sup> Department of Medicine (Dermatology), University of Toronto, Toronto, Ontario, Canada<sup>b</sup> University Health Network, University of Toronto, Toronto, Ontario, Canada<sup>c</sup> Department of Family Medicine, University of Ottawa, Ottawa, Ontario, Canada<sup>d</sup> The Rockefeller University, New York, United States<sup>e</sup> Department of Psychology, York University, Toronto, Ontario, Canada<sup>f</sup> Division of Dermatology, Women's College Hospital, Toronto, Canada

## ARTICLE INFO

## Article history:

Received 4 August 2017

Received in revised form 11 October 2017

Accepted 15 October 2017

Available online xxx

## ABSTRACT

**Background:** Hidradenitis suppurativa (HS) is a chronic, recurrent, debilitating follicular disease. The effect of HS on physical and psychological aspects of sexual function is not well understood.**Objective:** The objective of this study is to investigate the contribution of sexual dysfunction to the quality of life (QoL) of patients with HS and to investigate the extent to which sexual health predicts the QoL in these patients.**Methods:** This is an observational cross-sectional study of 50 patients with HS and 50 healthy volunteers who completed questionnaires to measure QoL and sexual functioning using four validated tools.**Results:** Male patients experienced higher sexual dysfunction and a reduced quality of sexual life, while female patients reported higher sexual distress, compared with control groups. In male patients, sexual QoL and erectile dysfunction predicted a 72% decline in QoL. In female patients, sexual distress and sexual dysfunction predicted 46% variability in QoL index scores, beyond the effects of disease severity.**Conclusion:** Disruptions to sexual functioning greatly contribute to QoL impairments in patients with HS regardless of genital lesions. Health care professionals should inquire about and pay close attention to sexual health concerns in patients with HS.© 2017 The Authors. Published by Elsevier Inc. on behalf of Women's Dermatologic Society. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

## Introduction

Hidradenitis suppurativa (HS) significantly impairs patients' quality of life (QoL; Jemec and Wulf 1996; Jemec et al. 1996; von der Werth and Jemec 2001) with greater disability than many other dermatological conditions (Balieva et al. 2017; Wolkenstein et al. 2007). HS is characterized by recurrent, painful, inflammatory nodules in intertriginous regions of the body such as the axillary, inguinal, inframammary and anogenital regions (Deckers and Kimball 2016). These symptoms, exacerbated by malodorous discharge and pain

(Esmann and Jemec 2011), hinder patients' sexual function and intimacy in interpersonal relationships, particularly in the younger population (Sampogna et al. 2017). Many patients with HS experience feelings of embarrassment, shame, diminished self-worth, and isolation as a result of the associated smell, itching, pain, and scarring (Matusiak et al. 2010). A two-fold increase in risk of completed suicides in patients with HS has been recently reported, although the underlying contributing factors are yet to be explored (Garg et al. 2017).

Sexual health encompasses both the physical component of sexual functioning as well as the psychological component of an individual's subjective experience of sexuality (Verschuren et al. 2010). Overall genital involvement in any dermatological disease is associated with higher sexual distress (Sampogna et al. 2017; Van De Nieuwenhof et al. 2010). Therefore, it is not surprising that HS disproportionately affects patients' sexual health (Janse et al. 2017), which is an important determinant of overall QoL (Verschuren et al. 2010). Sexual health impairment is strongly linked with psychological disturbances that lead to depression, anxiety, and suicidal ideation in

<sup>☆</sup> Sources of support: None.

<sup>☆☆</sup> Conflicts of interest: Dr. Alavi is an advisor, consultant, and speaker for AbbVie, Janssen, LEO, Galderma, Novartis, and Valeant. She is also an investigator for AbbVie, Novartis, Regeneron, Pfizer, Boehringer-Ingelheim, Glenmark, Merck Serono, Roche, Xoma, and Xenon. She received an unrestricted educational grant from AbbVie. All other authors have no conflicts of interest to disclose.

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<https://doi.org/10.1016/j.ijwd.2017.10.007>

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Please cite this article as: Alavi A, et al, Quality of life and sexual health in patients with hidradenitis suppurativa, *International Journal of Women's Dermatology* (2017), <https://doi.org/10.1016/j.ijwd.2017.10.007>

patients with HS, even after controlling for other comorbidities such as obesity, diabetes, and thyroid disorders (Deckers and Kimball 2016; Sampogna et al. 2017).

Although the impact of HS on patients' sexual health has been gaining more attention in recent years, the literature on this topic remains limited. Our objective was to evaluate the extent to which impairments in sexual health adversely affect QoL in patients with HS compared with healthy individuals. Given that HS disproportionately affects female patients, sex differences in the level of QoL impairment were also explored in this study. We hypothesized that both the physical and psychological aspects of sexual functioning predict QoL in patients with HS. We confirmed that HS significantly reduced the QoL of both male and female patients and found that sexual dysfunction was a major contributor that could predict this negative impact on QoL.

## Methods

### Study design and participants

This observational cross-sectional study included 50 patients with HS and 50 controls who were matched for age and sex. The study was approved by the Women's College Hospital research ethics board in Toronto, Ontario, Canada. The inclusion criteria for the HS group included the ability to give informed consent, > 18 years of age, and a diagnosis of HS confirmed by a dermatologist. Disease severity was assessed with the Hurley staging system by a dermatologist during the clinic visit. Eligible patients with HS who presented at the Women's College Hospital or the Richmond Hill Dermatology Clinic between October 2015 to 2016 were recruited to complete self-administered paper questionnaires.

The control group was composed of healthy individuals or individuals who accompanied the patient and who were matched for age and sex on the basis of self-reports. The individuals in the control group did not have HS or any known medical conditions, including HS comorbidities. Patients or healthy volunteers who had any other chronic dermatologic conditions during the past year or any malignant, psychiatric, or hormonal disorders were excluded.

### Quality of life and sexual health questionnaires

The primary outcomes of interest were overall QoL and sexual functioning. Four validated sexual health questionnaires were used to qualitatively assess the physical and psychological aspects of sexual functioning. The validated instruments that were utilized to evaluate QoL and sexual functioning included the Dermatology Life Quality Index (DLQI), Sexual Quality of Life Questionnaire for Use in Men (SQoLM), International Index of Erectile Dysfunction (IIEF), Female Sexual Function Index (FSFI), and Female Sexual Distress Scale – Revised (FSDS-R).

The DLQI is a validated, 10-item questionnaire that evaluates the QoL of patients with a dermatological disease. The questionnaire encompasses six domains: symptoms and feelings, daily activities, leisure, work and school, personal relationships, and disease management. There is a question on sexual health in the DLQI, but the DLQI has been validated for use as a single 10-question tool. The total score is calculated by summing the scores of each question (minimum = 0, maximum = 30). The higher the DLQI score, the more QoL is impaired (Finlay and Khan 1994).

The SQoLM is a self-administered instrument that is used to assess the sexual QoL in men and was completed by male participants. The instrument contains 11 items, each on a six-point response scale. The total scores are calculated in accordance with the SQoLM scoring manual (minimum = 0, maximum = 100). Higher scores denote a higher QoL (Abraham et al. 2008).

The IIEF was completed also by the male participants. The IIEF is a 15-item questionnaire that assesses five domains of male sexual function: erectile function, orgasmic function, sexual desire, intercourse satisfaction, and overall satisfaction. The scores for individual items are summed in accordance with the scoring manual (minimum = 5, maximum = 75). Higher scores indicate better sexual function (Rosen et al. 2000).

The FSDS-R is a questionnaire that was completed by the female participants. The FSDS-R questionnaire is composed of 13 items that measure sexually related distress in women. The FSDS-R differs from the FSDS in that it includes an item on distress that is related to low sexual desire. The minimum possible score is 0, and the maximum possible score is 52. An FSDS-R score of  $\geq 11$  indicates female sexual dysfunction. Higher scores indicate greater sexual dysfunction (Derogatis et al. 2008).

The Female Sexual Function Index (FSFI) was completed also by female subjects and consists of a 19-item questionnaire that assesses six domains of female sexual function: sexual desire, arousal, lubrication, orgasm, satisfaction, and pain. Scores are calculated by adding the six domain scores (if one or more items of a domain are missing, a domain score is not calculated). The minimum possible score is 2, and the maximum possible score is 36. FSFI total scores of  $\leq 26.55$  indicate sexual dysfunction. Higher scores indicate better sexual functioning (Rosen et al. 2000; Wiegel et al. 2005).

### Statistical analysis

Outcome variable scores were evaluated in accordance with the individual instrument criteria (ie, DLQI, SWoL-M, IIEF, FSFI, and FSDS-R). The statistical analysis was performed using SPSS Statistics, Version 23 (IBM, Armonk, NY). Continuous variables were described as mean  $\pm$  standard deviation, and discontinuous variables were described by total frequencies and percentages of each modality. The differences between patients in the HS and control groups were evaluated with a  $\chi^2$  test for categorical variables. Continuous variables were compared with independent Student's *t* tests. Pearson correlation tests were conducted to assess the effect size for the association between variables. Two-sided statistical significance was assessed at  $p < .05$ .

A hierarchical regression analysis was used to examine the influence of predictor variables sequentially (Cohen 2008), such that the relative importance of sexual health in predicting QoL could be deciphered, over and above the contribution of disease severity. This analysis was performed separately for male and female patients due to the differences in sexual function instruments.

Hurley stage and the current number of lesions were used to account for disease severity. In simple terms, hierarchic regression is the same as multiple regression when performed in separate steps, such that certain predictors have the first chance to explain the outcome of interest. Any additional predictors have to provide a useful explanation or predictive ability beyond what has already been accounted for by the preceding steps. We used this method to show that the sexual distress and dysfunction scales predict impairment in the QoL of patients beyond what can already be explained using the extent of their disease progression and current number of lesions.

## Results

Patients with HS had a significantly lower QoL as measured with the DLQI compared with the control group ( $p < .0001$ ; Fig. 1). The DLQI scores of male and female patients with HS did not differ, but they were significantly different when compared with those of the same sex control group.

The demographic characteristics of both patients with HS and healthy controls were very similar in the study (Table 1). In the HS cohort, the female-to-male ratio was 3:1.5 and the mean age was

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