



## Review

# Gender differences in sexual health impairment in hidradenitis suppurativa: A systematic review



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## ABSTRACT

Hidradenitis suppurativa (HS) is a chronic inflammatory dermatosis characterized by painful nodules, sinus tracts, and scarring, with a predilection for intertriginous areas. HS is particularly prevalent in women of childbearing age and can have varying psychological and physical consequences. The chronic and debilitating nature of this disease can lead to significant impairments in patients' sexual health and overall quality of life. This systematic review examines gender differences in the impact of HS on sexual health. In addition, we review gaps in the management of sexual health for patients with HS and outline recommendations to adequately address sexual concerns and optimize care.

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## Introduction

Hidradenitis suppurativa (HS) is a chronic, debilitating, inflammatory disease that disproportionately affects women, those age 30 to 39 years, African Americans, and biracial patient groups (Garg et al., 2017). HS is characterized by recurring, deep-seated, inflamed nodules that can progress to chronic draining sinus tracts with significant scarring and disfigurement (Danby and Margesson, 2010).

*Sexual distress* is defined as negative emotions about sex, such as regret, frustration, guilt, and unhappiness (Alavi et al., 2018b; Andersen et al., 2020; Cuenca-Barrales et al., 2019; Janse et al., 2017; Sampogna et al., 2017). On the other hand, *sexual dysfunction* refers to impairments in the physical aspects of sexual activity, such as lubrication, penetration, maintenance, orgasm, and resolution. *Sexual health impairment* includes both sexual distress and sexual dysfunction.

Patients with HS often report sexual health impairments stemming from both the psychological and physical consequences of having this disease (Esmann and Jemec, 2011). Contributing psychological impairments include depression, embarrassment, fear of contagion, and shame. Physical impairments include pain, drainage, pruritus, scarring, and malodor (Esmann and Jemec, 2011).

Studies on other chronic dermatologic diseases, such as psoriasis, have found that sexual health impairment is particularly prominent in women (Ermercan, 2009; Gottlieb et al., 2019; Meeuwis et al., 2011). Few studies have specifically investigated how the sexual health of women and men may be differentially affected by HS. This review examines the existing literature on gender differences in sexual health in patients with HS, identifies practice gaps, and provides strategies for improving sexual health care.

## Methods

A literature search using the PubMed and Embase databases was conducted on April 28, 2020, using the terms (“hidradenitis” or “hidradenitis suppurativa” or “acne inversa” or “verneuil disease” or “velpeau disease”) AND (“sex” or “sexual” or “sexuality” or “sexual health” or “sexual function” or “sexual dysfunction” or “sexual impairment” or “sexual well-being” or “sexual experience” or “sexual activity” or “intimacy” or “sexual behavior” or “relationship” or “marriage” or “partner” or “desire” or “libido” or “arousal” or “orgasm” or “ejaculation” or “impotence” or “erectile dysfunction” or “sexual motivation” or “sexual dissatisfaction” or “sexual satisfaction” or “dyspareunia”). The results were screened further to include only articles in the English language. Studies were excluded if they were duplicates, did not study HS, and/or did not discuss the sexual health effects of HS. Reviews, meta-analyses, conference abstracts, and commentary pieces were also excluded. Two independent reviewers (EC and DY) identified the final set of articles for inclusion. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram depicts our literature search schema in Fig. 1. Study design, patient demographics, study instruments, and study results were extracted. Two sets of data extractions were done for each article (EC or DY and JJ).

## Results

A total of 789 citations were identified from our literature search. (Fig. 1). Of these, 13 articles met the inclusion criteria (Supplementary Table 1). The study instruments used in these papers are described in Supplementary Table 2.

## Effects on sexual distress and sexual function

Patients with HS experience significant impairments in sexual function compared with patients without HS (Alavi et al., 2018b; Cuenca-Barrales et al., 2019; Janse et al., 2017; Kurek et al., 2012). Men with HS have been shown to experience a significantly lower sexual quality of life (QoL;  $p < .0001$ ) and function ( $p = .019$ ) compared with patients without HS, as measured by the Sexual Quality of Life Questionnaire for Use in Men and International Index of Erectile Function, respectively (Alavi et al., 2018b). Similarly, when compared with women without HS, women with HS have also been shown to experience a significantly higher measure of sexual distress ( $p = .002$ ; Alavi et al., 2018a) and lower sexual function (22.1 vs. 29.0;  $p = .01$ ; Kurek et al., 2012), as measured by the Female Sexual Distress Scale-Revised and Female Sexual Function Index, respectively. One survey study reported several reasons for this decline in sexual health, including influence on physical appearance (89% for women vs. 79% for men), fear of partner transmission (49% for women vs. 60% for men), diminished sexual desire of patient (90% for women vs. 87% for men) or of patient's partner (49% for women vs. 60% for men), and fear of vertical transmission of HS to children (51% for women vs. 27% for men; Janse et al., 2017).

When compared to men, women have significantly higher sexual distress, indicated by a lower Frankfurt Body Concept Scale for Sexuality score (19.5 for women vs. 23.5 for men;  $p = .02$ ), greater impact on sex life from HS (7.24 for women vs. 6.39 for men;  $p = .021$ ) as measured by the Numeric Rating Scale, and worse overall sexual health as indicated by a higher Arizona Sexual Experience Scale score (17.4 for women vs. 14.0 for men;  $p < .001$ ; Table 1; Cuenca-Barrales et al., 2019; Janse et al., 2017; Kurek et al., 2012). Older men have a higher incidence of sexual dysfunction compared with younger men, and women with a disease onset at an older age were found to have higher sexual dysfunction (Cuenca-Barrales and Molina-Leyva, 2020; Janse et al., 2017).

## Quality of life

Patients with HS experience diminished overall QoL when compared with healthy controls (Alavi et al., 2018b). When compared with the general population, there are statistically significant disease-associated impairments with sleep ( $p = .002$ ), vitality ( $p < .001$ ) and sexual activity ( $p < .001$ ) as measured by the 15D (Kluger et al., 2018). Patients with higher disease severity have been found to have more impaired QoL (Sartorius, Dermatology Life Quality Index [DLQI];  $r = .38$ ;  $p = .01$ ; Janse et al., 2017; Kurek et al., 2012). Impairment in QoL for both men (7.31 vs. 5;  $p < .01$ ) and women (8.27 vs. 6.17;  $p < .0001$ ) was found to be significantly greater in those with existing sexual dysfunction or erectile dysfunction than in those without sexual impairments as measured by the Numeric Rating Scale (Cuenca-Barrales et al., 2019). Most studies found no statistically significant difference in QoL between men and women (Janse et al., 2017; Sampogna et al., 2017; Sisic et al., 2017); however, two studies indicated that women had a significantly lower QoL compared with men as indicated by higher DLQI scores (11.63 for women vs. 3.00 for men;  $p = .001$ ; 14.4 for women vs. 6.9 for men;  $p = .03$ ; Kluger et al., 2018; Kurek et al., 2012).

Another cause of reduced QoL is malodorous discharge, reported by 88% of patients with HS (Alavi et al., 2018a). Odor severity significantly predicted the total Skindex score after controlling for disease severity ( $p < .0001$ ) but did not predict DLQI ( $p = .064$ ). Although men, on average, had a higher odor severity than women, the authors could not conclude a gender difference in impact on QoL based on odor (Alavi et al., 2018a). Presence of malodor is associated with significantly greater sexual distress



## PRISMA 2009 Flow Diagram

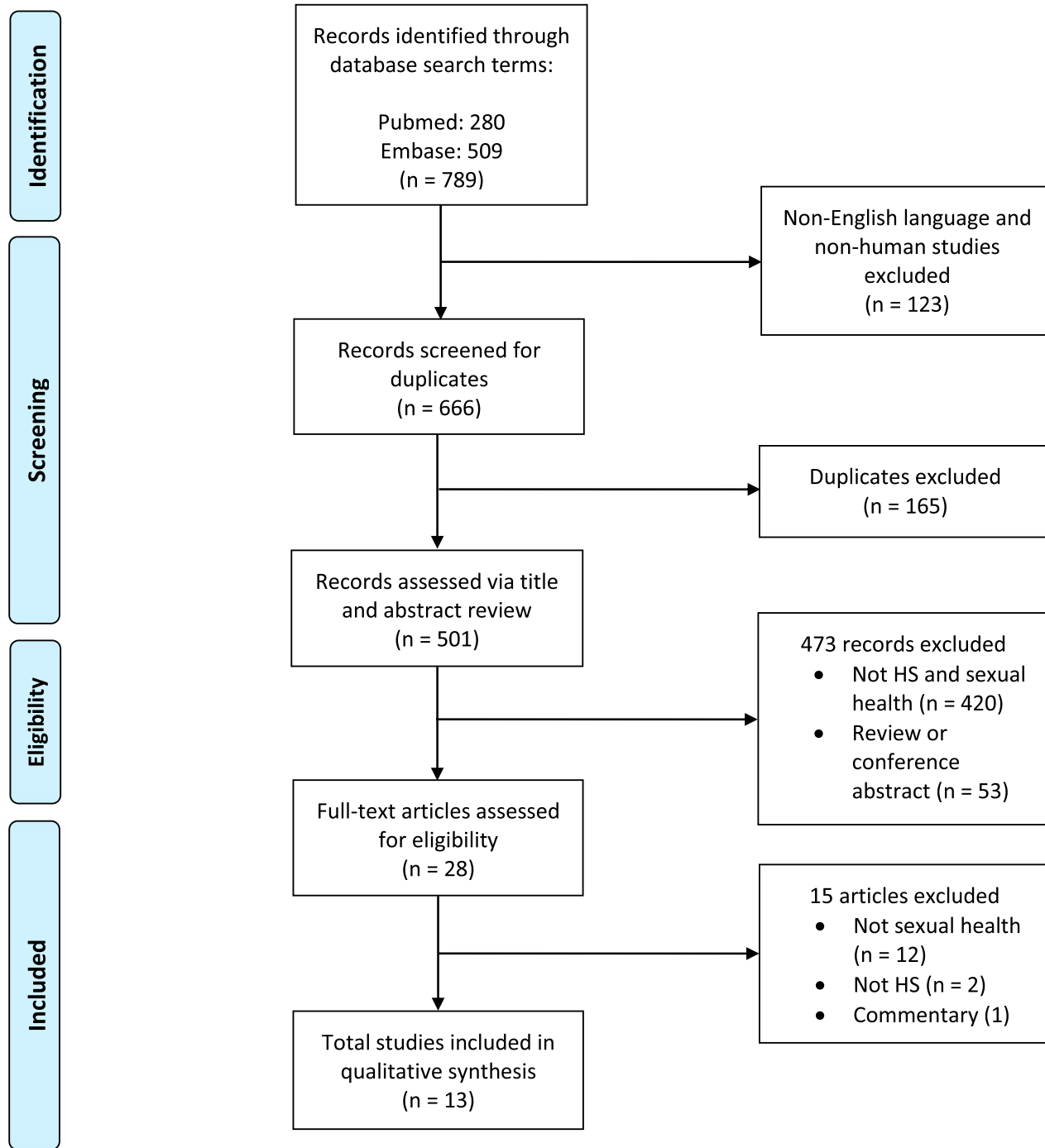


Fig. 1. Preferred reporting items for systematic reviews and meta-analyses flow diagram.

(all patients with HS:  $p = .035$ ; female patients with HS:  $p < .05$ ; Alavi et al., 2018a; Cuenca-Barrales et al., 2019; Cuenca-Barrales and Molina-Leyva, 2020).

Finally, surgical intervention is typically reserved for severe recalcitrant disease. One study found that surgical intervention produced lasting improvements in QoL overall, but not in sexual functioning (Prens et al., 2019).

### Mental health

In a cross-sectional study of 26 patients with HS, 38.5% of those surveyed (9 women and 1 man) reported depression symptoms (Kluger et al., 2018). This study also found that women had significantly more severe depressive symptoms compared with men, as measured by their higher Beck Depression Inventory score (15 for

**Table 1**  
Gender differences in impact of hidradenitis suppurativa on sexual health impairment (including sexual distress and sexual dysfunction).

Domain	Study	Study findings
Sexual distress (negative emotions about sex such as regret and frustration) and sexual dysfunction (impairments in the physical aspects of sexual activity)	Kurek et al., 2012 Cuenca-Barrales et al., 2019 Janse et al., 2017	FKKS SSEX: 19.5 F vs. 23.5 M ( $p = .02$ ) despite comparable disease severity NRS for HS impact on sex life: 7.24F vs. 6.39 M ( $p < .05$ )
	Slyper et al., 2017	ASEX: 17.4 F vs. 14.0 M ( $p < .001$ ); correlation between age of HS onset and ASEX in women ( $r = -.25$ ; $p < .001$ ); no such correlation in men 1.0% F vs. 3.9% M incidence of sexual dysfunction ( $p = .20$ ) with higher incidence among those with depressive (2.4%; $p = .03$ ) or anxiety ( $p < .001$ ) disorder
	Prens et al., 2019	Mean ASEX score of 15.4 and no difference between genders ( $p = .77$ )
	Janse et al., 2017; Kurek et al., 2012 Kluger et al., 2018 Kurek et al., 2012 Alavi et al., 2018a	Significant association between sexual health and quality of life seen in women but not men DLQI: 11.6 F vs. 3.0 M ( $p = .001$ ) DLQI: 14.4 F vs. 9.6 M ( $p = .03$ ) Odor severity was not a predictor of DLQI ( $p = .064$ ) but did significantly predict the total Skindex score ( $p < .0001$ ). On average, M had higher odor severity than F.
Quality of Life		
Mental Health	Cuenca-Barrales and Molina-Leyva, 2020	Benzodiazepine use trended toward statistical significance in association with sexual dysfunction among women ( $p = .059$ )
Body Image	Andersen et al., 2020	Female sex was a predictor of negative Bi-QoL ( $p = .005$ )
Relationships	Cuenca-Barrales and Molina-Leyva, 2020 Sisic et al., 2017	Stable relationship was a significant protective factor against sexual dysfunction in women (OR: 0.36; $p < .001$ ) but not men Patients with HS significantly more likely to report IPV ( $p < .05$ ) compared with control patients (with acne). No statistically increased risk of sexual assault compared with controls.
	Włodarek et al., 2020	No significant gender difference in FDLQI scores (8.73 F vs. 8.66 M)
	Janse et al., 2017	Only 6% of patients with HS believed doctors paid enough attention to sexual problems
Practice gaps		

ASEX, Arizona Sexual Experience Scale; Bi-QoL, Body image quality of life; DLQI, Dermatology Life Quality Index; F, female; FDLQI, Family Dermatology Life Quality Index; FKKS SSEX, Frankfurt Body Concept Scale for Sexuality; HS, hidradenitis suppurativa; IIEF, International Index of Erectile Function; IPV, intimate partner violence; M, Male; NRS, Numeric Rating Scale; OR, odds ratio; r, Pearson correlation coefficient.

**Table 2**  
Recommendations to improve sexual health care for patients with HS.

All patients with HS	<ul style="list-style-type: none"> <li>• Inquire about sexual distress/dysfunction</li> <li>• Screen for depression and anxiety</li> <li>• Maintain heightened awareness for signs of intimate partner violence</li> <li>• Elicit and address disease-related concerns of patients' partners</li> <li>• Treat HS early and aggressively to prevent scarring and physical impairment</li> <li>• Recommend antiseptic washes and appropriate wound care dressings (e.g., calcium alginate, hydrofibers) to contain discharge and reduce odor</li> <li>• Encourage patients to communicate with their partners about HS and its effects on their sexual health</li> <li>• Educate patients and their partners that HS is not contagious</li> <li>• Refer to mental health or sexual health specialists as needed</li> <li>• Recommend couples therapy or marriage counseling as needed</li> <li>• Set appropriate expectations regarding potential lack of significant change in sexual functioning after surgical procedure</li> <li>• Connect patients with support groups and counseling to improve self-esteem and mental health</li> <li>• Integrate e-symptom trackers to monitor treatment outcomes</li> </ul>
Female patients with HS	<ul style="list-style-type: none"> <li>• Inquire about body image concerns</li> <li>• Use lubricants to mitigate discomfort from friction</li> <li>• Use tampons instead of menstrual pads to minimize discomfort from active groin lesions</li> </ul>
Male patients with HS	<ul style="list-style-type: none"> <li>• Inquire about erectile dysfunction</li> <li>• Refer for erectile dysfunction treatment if needed</li> </ul>

HS, hidradenitis suppurativa.

women vs. 0.906 for men;  $p = .001$ ). There is a higher sexual dysfunction incidence in patients with a preexisting depressive disorder (2.4% vs. 1.4%) or anxiety disorder (2.4% vs. 1.5%) (Slyper et al., 2018). When examining factors associated with sexual dysfunction in women with HS, Cuenca-Barrales and Molina-Leyva (2020) found that benzodiazepine use trended toward statistical significance ( $p = .059$ ), reflecting the likely contribution of anxiety in sexual health impairment.

### Body image

Patients with HS have significantly lower body image scores than patients with other skin diseases ( $-0.87$  vs.  $0.01$ ;  $p < .001$ ), and female sex was a significant predictor of low body image scores among patients with HS ( $p = .005$ ; Andersen et al., 2020). Patients with HS felt less acceptable as sexual partners and felt that they had a less enjoyable sex life compared with healthy controls.

Comorbid anxiety, marital status, and educational level were not found to be significant predictors of body image scores (Andersen et al., 2020).

### Relationships

Although HS imparts a significant burden on sexual health, support from an intimate partner can have a positive impact on the patient, especially for female patients. Stable relationships have been found to be a significant protective factor for sexual distress in women with HS (odds ratio [OR]: 0.36;  $p < .001$ ; Cuenca-Barrales et al., 2019). On the other hand, in a prospective study of 243 patients (67% women), patients with HS were significantly more likely to experience intimate partner violence (IPV) than controls (with acne; OR: 2.35;  $p < .05$ ; Sisic et al., 2017). No significant difference was found in sexual assault risk, but patients with HS were significantly more likely to report sexual abuse, as measured by responses to a subset of questions in the Checklist for Controlling Behaviors (OR: 2.03;  $p < .05$ ; Sisic et al., 2017). Partners of patients with HS are also affected by this disease; 82% of partners report QoL impairment, with no significant difference between male and female partners. Increases in patient disease severity correlate with QoL impairment in partners (Family Dermatology Life Quality Index; Hurley stage 1: 4.9; stage 2: 9.4; stage 3: 11.8; Wlodarek et al., 2020).

### Practice gaps

Patients with HS report being unsatisfied with the amount of attention physicians give to their sexual concerns. Only 6% of patients felt that their sexual concerns were given sufficient attention from their clinicians. Forty-four percent of patients reported that doctors did not adequately address their sexual concerns during their clinic appointments, and 34% of patients felt that doctors should dedicate more time and effort to their sexual health (Janse et al., 2017). Gender differences were not explored in this study.

## Discussion

Several studies have explored the impact of HS on patients' QoL and found notable impairments. There are significant impairments in the sexual health domain (Alavi et al., 2018b; Janse et al., 2017; Marasca et al., 2020); however, few studies to date have focused specifically on HS and sexual health. We identified 13 articles addressing sexual health in HS and subsequently investigated the gender differences noted in these studies.

Women with HS report higher sexual distress than men (Cuenca-Barrales et al., 2019; Janse et al., 2017; Kurek et al., 2012). Of note, distinguishing between sexual distress and sexual dysfunction may be helpful in both clinical practice and research; the former may indicate psychological harm, whereas the latter may suggest poor physical experience. Factors contributing to women experiencing higher sexual distress may include social stigmas, increased risk of negative body image, differences in sexual arousal and physiology, and differences in anatomic distribution of HS.

Psychosocial and cultural expectations on women's physical appearance are often distinct from those of men. The majority of women report that sexual health declined due to the disfigurement of their physical appearance from HS (Janse et al., 2017). Women may also experience a higher pressure to modify behavior based on physical appearance (Kurek et al., 2012). Body image has a direct correlation with sex life in women (Peplau et al., 2009). Women tend to have a more negative body image and greater self-consciousness specific to sexual encounters compared with

their male counterparts (Milhausen et al., 2015). Women are more likely than men to allow their appearance to inform their behaviors and are more likely to engage in behaviors that divert attention from their appearance or to avoid sexual encounters due to body image (Milhausen et al., 2015). One potential anatomic reason for the higher levels of sexual distress in women is that active genitofemoral lesions have been found to occur significantly more often in women than men (OR: 5.4;  $p = .004$ ; Jemec et al., 1996; Kurek et al., 2012).

Patients with HS are more likely to experience IPV than controls (Sisic et al., 2017). Although there was no gender-specific data for patients with HS, women are more susceptible to IPV than men. One in four women and one in 10 men experience contact sexual violence, physical violence, and/or stalking by an intimate partner and reported IPV-related impact Centers for Disease Control and Prevention. National intimate partner and sexual violence survey (2015). Clinicians should consider screening patients with HS, especially women, for IPV using a validated screening tool.

Patients may feel embarrassed to discuss sexual health with their physicians, which can lead to underreporting of symptoms and potential study biases. Anonymizing survey studies may help mitigate underreporting. Janse et al. (2017) found that 44% of patients with HS believed their doctors inadequately addressed sexual health concerns. Although the study did not comment on male versus female responses, the majority of respondents were female (3.5:1). This suggests that there is a practice gap in physician counseling and management of patients' sexual health that warrants further study and discussion. The role of gender in this gap remains to be elucidated.

Practice gaps can be narrowed by incorporating questions about sexual health into routine clinic visits with patients with HS, including inquiring about the patient's relationships and partner well-being. Additional strategies for improving delivery of sexual health care to patients with HS are listed in Table 2. Patients with HS and non-health care professionals may erroneously believe that HS is an infectious, contagious, and/or sexually transmitted condition (Finlay and Khan, 1994; Janse et al., 2017). Increased public awareness of HS and improved patient and partner education are paramount to prevent misinformation and remove stigma. Encouraging open communication between patients and their partners may help foster trust and mitigate sexual impairment.

Finally, the studies in this review employed a variety of instruments to quantify the effect of HS on sexual health. Differing instruments make comparing results across studies challenging and introduce the possibility of source bias. Instruments also varied between male and female study participants. For example, the two most commonly used scales for women, the Female Sexual Function Index and Female Sexual Distress Scale-Revised, focus on both physical and emotional aspects of sexual health, including questions such as "How stressed are you about sex?" The male-specific scales tend to focus on physical aspects, such as erection quality, erection maintenance, and sexual satisfaction during intercourse. These differences may lead to potential gender biases in the results. Standardization of sexual health instruments and use of a common set of measures for both female and male patients in studies on HS are needed to draw more accurate comparisons. Sexual health should routinely be incorporated as an outcome measure in trials on HS.

## Conclusion

HS is a highly burdensome, chronic disease that is significantly associated with impairments in sexual health across various validated instruments in both male and female patients. Sexual health burden from HS appears to be higher for women. Additional stud-

ies are needed to further elucidate the differential impact of HS on sexual impairment by gender. This may also shed light on targeted interventions that may be beneficial for women or men. QoL impairments due to sexual health can be mitigated with proactive physician questioning and counseling about sexual health in all patients with HS, regardless of whether genital lesions are present. Sexual health should be addressed when assessing HS severity and treatment outcome. Increased awareness of sexual impairment in HS is paramount to optimized care.

### Conflicts of interest

Dr Vivian Y. Shi is a stock shareholder of Learn Health and has served as an advisor, investigator, and/or speaker for Sanofi Genzyme, Regeneron, AbbVie, Burt's Bees, Dermira, Eli Lilly, Novartis, Pfizer, Galderma, Leo Pharma, SUN Pharma, Menlo Therapeutics, GpSkin, and Skin Actives Scientific. There was no financial transaction for the preparation of this manuscript. All other authors report no conflicts of interest.

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N/A.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijwd.2020.10.010>.

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