

Research Article

Relationship Disturbances in Hidradenitis Suppurativa: A Patient Perspective

Alyssa M. Thompson^{*a}, Jonathan W. Rick^{*b}, Devea R. De^c, Jennifer M. Fernandez^d, Melody Maarouf^e,
Justine R. Seivright^f, Jennifer L. Hsiao^g, Vivian Y. Shi^b

*equal contribution/co-first authors.

- a. College of Medicine, University of Arizona, Tucson, (AZ,) USA
- b. Department of Dermatology, University of Arkansas for Medical Sciences, Little Rock, (AR,) USA
- c. Jacobs School of Medicine and Biomedical Sciences, University at Buffalo, Buffalo, (NY,) USA
- d. University of Nebraska Medical Center, Department of Dermatology, Omaha, (NE,) USA
- e. Department of Medicine, Division of Dermatology, University of Arizona, Tucson, (AZ,) USA
- f. David Geffen School of Medicine, University of California, Los Angeles, (CA,) USA
- g. University of Southern California, Department of Dermatology, Los Angeles, (CA,) USA

Short Title: Relationship Disturbances in Hidradenitis Suppurativa: A Patient Perspective

Corresponding Author:

Vivian Y. Shi

Associate Professor

Department of Dermatology

University of Arkansas for Medical Sciences

4301 W. Markham St., #576

Little Rock, AR 72205-7199

Phone: (501) 526-6994 | Fax: (501) 686-7264

Email: vivian.shi.publications@gmail.com

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1 **Abstract:**

2 Introduction:

3 Hidradenitis suppurativa can significantly impact patients' relationships.

4 Methods:

5 Using an anonymous electronic survey, we aimed to determine what aspects of sexual relationships are
6 affected by HS discomfort and patients' reluctance to discussing HS with their partner.

7 Results:

8 Among the 873 participants, 60.9% reported that some aspect of their relationship was affected by HS
9 discomfort, with the greatest being their sexual encounters with spouse (49.1%). Furthermore, 43.0%
10 (320) of participants reported feeling reluctant to discuss HS with their spouse/significant other, with
11 the more common reason being fear of partner seeing boils and scars (84.7%). Multiple aspects of
12 relationships can be affected by HS such as sexual encounters, overall relationship, and finding a
13 relationship. Additionally, several communication barriers are present, such as fear of partner seeing
14 boils and scars, partner thinking they had an infection such as a sexually transmitted disease, and fear of
15 bloody or malodorous drainage, among others. The presence of anogenital pain, Hurley stage, gender,
16 and age significantly affect these findings.

17 Discussion/Conclusion:

18 Addressing HS related relationship disturbances should be included in HS management.

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23 **Introduction:**

24 Hidradenitis suppurativa (HS) is a chronic dermatosis characterized by painful abscesses, sinus tracts,
25 and scarring typically in intertriginous regions. HS has been associated with a decrease in quality of life
26 (QoL) and sexual health [1]. There is limited literature on intimate relationships affected by HS and
27 challenges present when discussing HS in relationships. Herein, we aimed to determine what aspects of
28 sexual relationships are affected by HS discomfort and patients' reluctance to discussing HS with their
29 partner.

30 **Methods:**

31 An anonymous electronic survey was distributed in North American HS specialty clinics and to Facebook
32 HS support groups between December 2017 and June 2019. Participants answered a series of
33 demographic questions and self-reported their Hurley stage based on written descriptors. In the survey,
34 Hurley stage 1 was defined as "single or multiple boil formation without tunnel formation and scarring",
35 Hurley stage 2 was defined as "recurrent single or multiple boils, widely separated, with limited tunnel
36 formation and scarring" and Hurley stage 3 was defined as "diffuse or widespread involvement of
37 multiple interconnected tunnels and boils". Participants were then asked to select all that applied to
38 what aspects of your life are affected by your discomfort (pain or itch) and why they felt reluctant to
39 discussing HS with their spouse or significant other. Statistical analyses were performed using JMP®
40 (Version-14.0. SAS Institute Inc., Cary, NC). Categorical data was evaluated with Pearson's chi-squared
41 test.

42 **Results:**

43 There were 873 participants (90.0% female) with a mean age of 35.7 and a mean BMI of 35.0. The
44 majority of the participants reported being white (70.6%), followed by Hispanic (9.7%), and African
45 American (9.2%). 51.2% of participants were married, 38.9% were never married, and 9.9% were

46 divorced. Most of the participants reported being Hurley-2 (51.0%), followed by Hurley-3 (35.9%), and
47 Hurley-1 (13.0%) (Table 1).

48 Aspects of Relationships Affected by Discomfort:

49 60.9% (532) of participants reported some aspect of their relationship was affected by HS discomfort,
50 including their sexual encounters with spouse [49.1% (429)], relationship with spouse/partner [34.5%
51 (301)], and ability to find a relationship [20.1% (176)].

52 Hurley-3 participants were significantly more likely to report that HS discomfort has affected their
53 relationship with spouse/partner (73.0 vs 60.1%; $p=0.0003$), their sexual encounters with spouse (61.6
54 vs 47.4%; $p<0.0001$) and their ability to find a relationship (25.3 vs 19.2%; $p=0.04$) than Hurley-1 and 2
55 participants. Patients with pain from HS in the anogenital area were significantly more likely to report
56 that HS discomfort affected their ability to find a relationship (25.4 vs 5.2%; $p<0.0001$), their relationship
57 with their spouse/partner (43.7 vs 8.7%; $p<0.0001$) and their sexual encounters with spouse (64.4 vs
58 10.3%; $p<0.0001$) (shown in Fig 1). Females were significantly more likely to report an effect on their
59 relationship with spouse/partner (35.8 vs 22.4%; $p=0.04$) and on their sexual encounters with spouse
60 (50.1 vs 40.0%; $p=0.02$) due to HS discomfort than males. Participants <30 years-old were significantly
61 more likely to report HS discomfort affected their ability to find a relationship than those ≥ 30 years-old
62 (54.5 vs 45.5%; $p=0.003$). Participants ≥ 30 years-old were significantly more likely to report that HS
63 discomfort affected their relationship with spouse/partner (38.5 vs 27.2%; $p=0.0007$) and their sexual
64 encounters with spouse (61.6 vs 47.4%; $p<0.0001$) than those <30 years-old (Table 2).

65 Reluctance to Discussing HS

66 Among the 43.0% (320) of participants that reported feeling reluctant to discuss HS with their
67 spouse/significant other, 84.7% (271) reported it was due to fear of potentially revealing their boils and
68 scars to their partner. Other reasons included : fear of partner thinking they had an infection such as a
69 sexually transmitted disease (STI) [59.7% (191)], fear of potentially having to reveal their bloody or

70 malodorous drainage to their partner [57.8% (185)], fear of pain during intercourse [34.4% (110)], fear
71 of sexual relationships worsening HS [28.4% (91)], and 13.4% (43) reported it was due to other reasons.

72 Hurley-3 participants were significantly more likely to report being reluctant to discuss HS with a
73 spouse/significant other due to fear of bloody or malodorous drainage (68.9 vs 51.3% **p=0.002**), fear of
74 their partner thinking they have an infection such as a STI (68.9 vs 54.3%; **p=0.01**) and fear of pain during
75 intercourse (42.2 vs. 29.7%; **p=0.02**) than Hurley-1 and 2. Patients with pain from anogenital
76 involvement were more likely to report reluctance to discuss HS with a spouse/significant other due to
77 fear of pain during intercourse (38.4 vs 20.6%; **p=0.004**), and fear of bloody or malodorous drainage
78 (64.4 vs 35.6%; **p<0.0001**). Females participants were significantly more likely to be reluctant to discuss
79 HS with a spouse/significant other due to fear of partner seeing boils and scars than males (86.4 vs
80 68.0%; **p=0.03**). Participants under 30 years-old were significantly more likely to be reluctant to discuss
81 HS with a spouse/significant other because they feared the partner would think they have an infection
82 such as a STI than those that were ≥ 30 (72.7 vs. 52.2%; **p=0.0003**). Participants that were ≥ 30 years-old
83 were significantly more likely to be reluctant to discuss HS with a spouse/significant (45.5% vs 41.6%;
84 **p=0.002**) than those that were < 30 years-old.

85 **Discussion:**

86 Our study demonstrates that a significant proportion of people who have HS may experience
87 disturbances in relationships and sexual function. More than 40% of participants are reluctant to discuss
88 HS with their spouse/partner most commonly due to fear of having to reveal their lesions to their
89 partner and fear of partner thinking they have an STI. As highlighted in Table 2, anogenital pain due to
90 HS, Hurley stage, gender, and age significantly influenced how HS discomfort affected participants'
91 relationships and their reasons for being reluctant to discuss HS.

92 Prior studies have also reported that female gender and genital/groin involvement are significantly
93 associated with sexual distress [2]. Furthermore, disease severity and anogenital involvement is

94 associated with an overall impairment in QoL [3]. Sexual disturbances may also be related to mental
95 health comorbidities commonly found in HS such as depression and anxiety. Prior studies have similarly
96 found that compared to healthy controls, HS patients feel less acceptable as a sexual partner, have a less
97 enjoyable sexual life, reduced sexual health, and diminished QoL [1,4]. Our current study builds upon
98 these findings by highlighting that in addition to sexual relationships, HS discomfort also affects patients
99 general relationship with spouse/partner and affects the ability to find new relationships. Furthermore,
100 sexual impairment is not limited to patients with HS, as their partners also report a diminished QoL [5].
101 Several studies have suggested healthcare providers address HS patients sexual health concerns [1,2,6–
102 9]. However, there is a paucity of literature addressing the importance of patient-partner
103 communication on relationship and sexual health improvement. Our study further identifies specific
104 reasons that patients may be reluctant towards these conversations, to help guide physicians on
105 appropriate patient education.

106 In our experience and observations conversations about HS with a spouse/partner is often challenging
107 due to the stigma and misinformation around the disease. Spending more time asking questions,
108 counseling, and educating patients on sexual health and relationships can reduce these challenges.
109 Specifically, educating patients and partners that HS is not a STI is important. Additionally, finding the
110 appropriate treatment plan to mitigate disfigurement, and discussing ways to minimize pain and
111 discharge during sexual encounters is beneficial. Ultimately, installing patient confidence through
112 education can help empower them to have open communication with their partner/spouse about HS
113 and improve their relationship.

114 Limitations of this study may include the predominantly female participants that may not fully represent
115 the sex distribution of HS, self-reported Hurley stages, voluntary response bias from individuals who
116 have experienced sexual impairments, and the responses from HS social media support groups may not
117 reflect the entire HS population.

118 **Conclusion:**

119 Addressing HS patient concerns about sexual health, relationships, and healthy communication
120 strategies is a necessary part of HS management. Referrals for individual and/or couple counseling may
121 be warranted. Future studies are needed to 1) identify strategies targeting the communication
122 challenges, education, and stigma around HS, 2) design treatment plans and measure outcomes, and 3)
123 strategically implement findings into clinical settings.

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140 **Statements**

141 **Statement of Ethics**

142 This study was deemed exempt by the University of Arizona Institutional Review Board. Informed
143 consent was not directly obtained but inferred by completion of the questionnaire/survey participation.

144 Consent to participate: N/A

145 Consent for publication: N/A

146 **Conflict of Interest Statement**

147 VYS is on the board of directors for the Hidradenitis Suppurativa Foundation (HSF), is a stock
148 shareholder of Learn Health and has served as an advisory board member, investigator, speaker, and/or
149 received research funding from Sanofi Genzyme, Regeneron, AbbVie, Eli Lilly, Novartis, SUN Pharma,
150 LEO Pharma, Pfizer, Incyte, Boehringer Ingelheim, Aristeia Therapeutics, Menlo Therapeutics, Dermira,
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153 directors for the Hidradenitis Suppurativa Foundation (HSF), and is a consultant for Novartis and speaker
154 for AbbVie

155

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158 **Author Contributions**

159 All authors meet the ICMJE Criteria for Authorship

160 **Data Availability Statement**

161 The datasets generated during and/or analyzed during the current study are available from the
162 corresponding author on reasonable request.

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Fig 1. Impact of Anogenital Pain on Patient Relationships