



Contents lists available at ScienceDirect

International Journal of Women's Dermatology



Original Research

Menses, pregnancy, delivery, and menopause in hidradenitis suppurativa: A patient survey

Jennifer M. Fernandez BS RD^a, Aleks J. Hendricks BS^a, Alyssa M. Thompson BS^a, Elizabeth M. Mata MSN^a, Erin K. Collier BS^b, Tristan R. Grogan MS^c, Vivian Y. Shi MD^d, Jennifer L. Hsiao MD^{e,*}^aUniversity of Arizona, College of Medicine, Tucson, AZ, United States^bUniversity of California Los Angeles, David Geffen School of Medicine, Los Angeles, CA, United States^cDepartment of Medicine Statistics Core, David Geffen School of Medicine, University of California, Los Angeles, CA, United States^dDepartment of Medicine, Division of Dermatology, University of Arizona, Tucson, AZ, United States^eDepartment of Medicine, Division of Dermatology, University of California Los Angeles, Los Angeles, CA, United States

ARTICLE INFO

Article history:

Received 13 February 2020

Received in revised form 21 June 2020

Accepted 2 July 2020

Keywords:

Hidradenitis suppurativa

Pregnancy

Menses

Menopause

Delivery

Cesarean section

ABSTRACT

Background: Hidradenitis suppurativa (HS) is a chronic inflammatory disorder that primarily affects women of childbearing age. There is a paucity of data on HS disease activity during menstruation, pregnancy, and menopause and the potential impact of HS on the method of delivery.

Objective: We aimed to characterize the natural history of HS symptoms during menses, pregnancy, and menopause. We also sought to evaluate the potential impact of HS on delivery method and whether there were delivery-related healing complications unique to women with HS.

Methods: An anonymous survey was distributed via social media to international HS support groups and patients at three HS specialty clinics in North America. Responses were collected from March to July 2019.

Results: A total of 279 respondents answered questions on disease changes during pregnancy. Menstruation caused worsening of HS symptoms in 76.7%, no change in 22.2%, and improvement in 1.1%. During pregnancy, the distribution between symptoms worsening (34.8%), having no change (28.7%), and improving (36.6%) was relatively even. After menopause, participants typically reported either worsening (39.5%) or no change (44.2%) in HS symptoms. Among respondents with anogenital HS involvement who delivered vaginally, 3.1% believed that HS interfered with vaginal delivery (VD), and 23.5% believed that VD caused an HS flare. Cesarean section (C-section) delivery was reported by 44.2% of participants. Ten participants reported that they were advised by their doctor to have a C-section instead of a VD because of severe anogenital HS. Of those who underwent a C-section, 33.9% reported that HS interfered with incision healing, and 51.2% reported developing new HS lesions in their C-section scar.

Conclusion: To our knowledge, this is the first study describing the potential influence of HS on a patient's method of delivery. Multidisciplinary collaboration plays a pivotal role in developing individualized treatment and birth plans for pregnant women with HS.

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Introduction

Hidradenitis suppurativa (HS), a chronic inflammatory dermatosis, is characterized by recurrent painful papules, nodules, and abscesses. It primarily affects intertriginous areas, such as the axilla, groin, genitals, and breasts. Diagnostic delay is a common problem in HS, and patients often suffer for many years before

receiving a formal diagnosis (Garg et al., 2020). HS disproportionately affects women of childbearing age, but despite this, there is a paucity of data on HS disease course during pregnancy. Previous studies have found that pregnant patients with HS were more likely to report no change in HS symptoms during pregnancy than improvement or worsening (Kromann et al., 2014; Vossen et al., 2017). We aimed to characterize the natural history of HS symptoms during menses, pregnancy, and menopause. A secondary objective was to identify the potential impact of HS on choice of delivery method and delivery-related healing complications.

* Corresponding author.

E-mail address: jhsiao@mednet.ucla.edu (J.L. Hsiao).

Methods

An anonymous questionnaire was administered at three HS specialty clinics in North America (University of Arizona in Tucson, University of California, Los Angeles, and University of California, Davis) and via social media to three international HS support groups (Hope For HS, the International Association of HS Network, and HS Warriors). This study was deemed exempt by the University of Arizona, Tucson, Institutional Review Board committee. Respondents who consented to participate were queried on demographic information and HS symptoms. Responses were collected using REDCap electronic data capture tools hosted at the University of Arizona (Harris et al., 2009, 2019) from March to July 2019. A total of 684 participants (women: n = 622) with a reported diagnosis of HS completed the version of the survey that included branching logic questions for menses, pregnancy, and menopause. A subset of 279 participants reported a history of pregnancy and therefore met inclusion criteria for this study.

To evaluate perceived HS disease status changes, participants were asked to indicate “improved,” “worsened,” “no change,” or “not applicable” to each of the following questions: “How do (or did) your HS symptoms change with your period?”; “How did your HS symptoms change during pregnancy?”; and “How did your HS symptoms change with menopause?” The results of the survey were summarized descriptively using average \pm standard deviation with ranges for continuous items and frequencies (percentages) for categorical responses. Responses of “not applicable” were not included in the analyses. The Spearman correlation was used to evaluate association of HS disease status during menses with HS disease status during pregnancy and during menopause. The χ^2 test was used to evaluate the association of HS during pregnancy with ethnicity, family history of HS, and delivery method. *P*-values of $<.05$ were considered statistically significant.

Results

The demographic and disease characteristics of the 279 female participants are summarized in Table 1. Mean age was 38.1 years (range, 19–74 years). Average age at the time of HS onset was 16.7 years (range, 1–59 years), and average age at the time of HS diagnosis was 28.4 years (range, 5–61 years). At the time of survey completion, the mean body mass index was 36.1 kg/m² (range, 17.9–68.1), and most participants had moderate-severe HS (9.3% Hurley stage I; 45.3% stage II; and 45.3% stage III).

HS symptom changes with menstruation, pregnancy, and menopause are depicted in Fig. 1. Of the 266 respondents, menstruation worsened HS symptoms in 204 respondents (76.7%), 59 respondents (22.2%) reported no change, and only 3 respondents (1.1%) reported an improvement. Symptom changes during pregnancy had a relatively even distribution among worsening (97 of 279 respondents; 34.8%), no change (80 of 279 respondents; 28.7%), and improvement (102 of 279 respondents; 36.6%). After the onset of menopause, the majority of participants reported either worsening of (17 of 43 respondents; 39.5%) or no change in (19 of 43 respondents; 44.2%) HS symptoms. There was a positive correlation between the severity of HS symptoms during menses and during pregnancy that trended toward significance (Spearman correlation: 0.115; *p* = .06). There was an inverse relationship between the severity of reported HS symptoms during menses and during menopause (Spearman correlation: -0.358 ; *p* = .02). There were no significant differences in HS symptoms during pregnancy based on ethnicity (*p* = .84), family history of HS (*p* = .87), or delivery method (*p* = .89).

Among the 162 participants with anogenital HS involvement who delivered vaginally, 3.1% (n = 5) believed that HS interfered

Table 1

Participant demographic information and survey responses.

Total participants (n = 279)	Mean \pm SD (range) or n (%)
Age, years (n = 279)	38.1 \pm 9.3 (19–74)
Age at time of onset, years (n = 279)	16.7 \pm 7.0 (1–59)
Age at time of diagnosis, years (n = 258)^a	28.4 \pm 9.6 (5–61)
Duration of disease, years (n = 257)^b	21.4 \pm 10.8 (1–58)
Body mass index, kg/m² at time of survey completion (n = 262)^c	36.1 \pm 9.0 (17.9–68.1)
Race/ethnicity (n = 279)	
White	215 (77.1)
Black	23 (8.2)
Hispanic	22 (7.9)
Native American	7 (2.5)
South Asian	3 (1.1)
Pacific Islander	1 (0.4)
Other	8 (2.9)
Reported Hurley stage at time of survey completion (n = 258)^d	
I	24 (9.3)
II	117 (45.3)
III	117 (45.3)
Positive family history of hidradenitis suppurativa (n = 279)	
Yes	112 (40.1)
No	72 (25.8)
Unknown	95 (34.1)
Cesarean section (n = 278)^e	123 (44.2)

SD, standard deviation

^a Twenty-one missing responses.

^b Twenty-two missing responses.

^c Seventeen missing responses.

^d Twenty-one missing responses.

^e One missing response.

with vaginal delivery (VD) and 23.5% (n = 38) believed that VD caused an HS flare (Fig. 2A). A Cesarean section (C-section) delivery was reported in 123 of 278 patients (44.2%). Physicians advised a C-section over VD in 10 participants due to severe groin or pubic HS involvement. Of participants who underwent a C-section, 33.9% (41 of 121) reported that HS interfered with incision healing, and 51.2% (63 of 123) reported developing new HS lesions in their C-section scar (Fig. 2B). Twelve of 115 participants (10.4%) were told their C-section incision needed to be placed more superiorly on the abdomen to avoid active HS lesions.

Discussion

We found that menses caused worsening of HS symptoms in the majority of participants, pregnancy had mixed effects, and menopause typically caused no change or worsening of HS symptoms. Our study also showed that HS may affect delivery method.

Given the predominance of women who reported that menses causes worsening of their HS symptoms, it is imperative for dermatologists to ask their female patients of childbearing age with HS whether menses is a trigger for their symptoms. Premenstrual HS flares have been reported by a range of 43% to 63% of patients in previous studies (Riis et al., 2016; Vossen et al., 2017), and the percentage of our cohort that reported such flares was even higher (76.7%). With the mean age at the time of HS onset and formal diagnosis at 16.7 and 28.4 years, respectively, our participants experienced a diagnostic delay of 11.7 years. Given that the mean age of menarche in the United States is approximately 13 years (McDowell et al., 2007), our findings suggest that >75% of women with HS spend several of their childbearing years experiencing

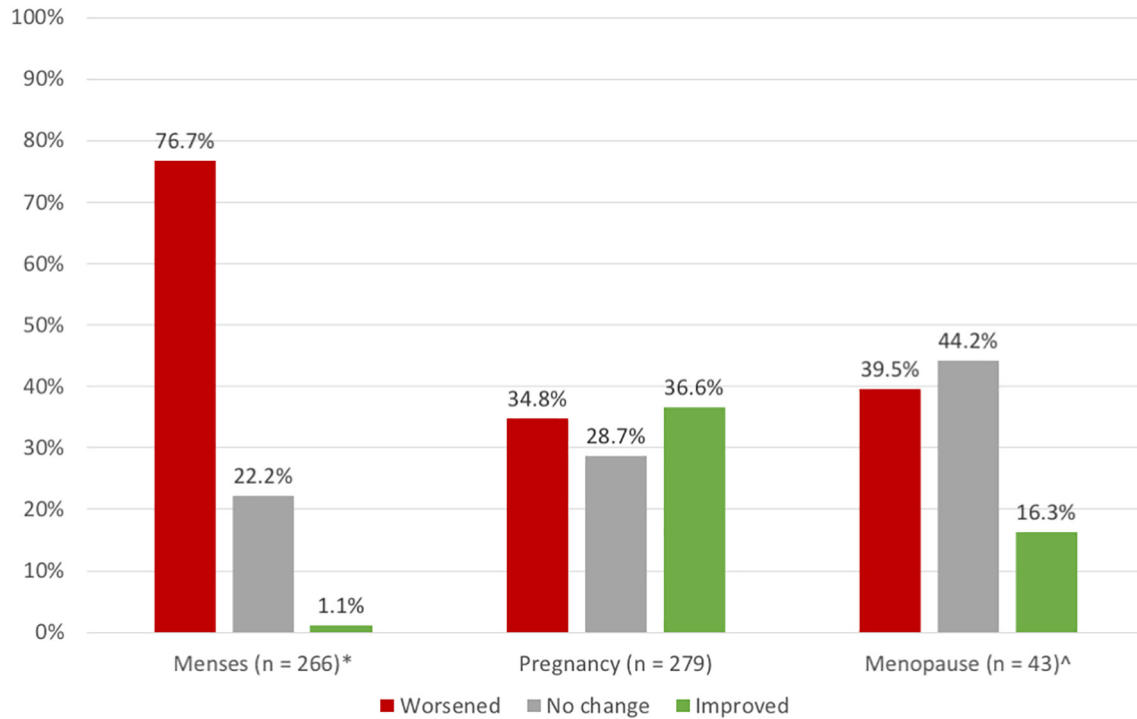


Fig. 1. Patient-reported change in hidradenitis suppurativa disease status in menses, pregnancy, and menopause. *Thirteen of 279 participants (4.7%) indicated not applicable. ^A total of 236 of 279 participants (84.6%) indicated not applicable.

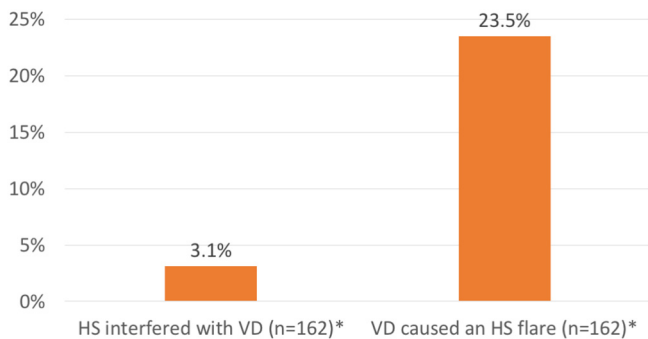


Fig. 2. (A) Vaginal delivery complications in patients with anogenital hidradenitis suppurativa. *A total of 117 of 279 participants (41.9%) indicated not applicable to these questions. (B) Cesarean-section delivery healing complications in hidradenitis suppurativa. *Missing two responses.

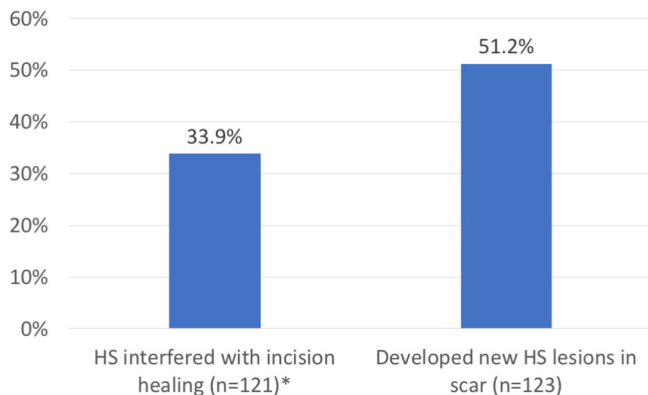


Fig. 2 (continued)

untreated perimenstrual HS flares. Earlier diagnosis of HS in adolescents is needed to mitigate this disease burden.

Two previous survey studies by [Kromann et al. \(2014; n = 85\)](#) and [Vossen et al. \(2017; n = 96\)](#) reported that pregnancy was more likely to cause no change in symptoms (72% and 53.1%, respectively) rather than an improvement (20% and 30.2%, respectively) or worsening (8% and 16.7%, respectively). In contrast, our study found worsening of symptoms to be more common during pregnancy (34.8%), with a smaller percentage reporting no change (28.7%). Pregnancy can have both anti-inflammatory and proinflammatory effects in HS, which may explain this even distribution. Anti-inflammatory effects are hypothesized to originate from decreased levels of interleukin-1 and tumor necrosis factor-alpha in addition to the downregulation of Th17 in the setting of increased progesterone ([Perng et al., 2017](#)). Proinflammatory effects may stem from increased estrogen levels, which may cause an increase in Th1 activity ([Perng et al., 2017](#)). Hormonal changes may modulate disease activity during pregnancy, but weight gain and inflammatory cytokines from adipocytes may also contribute to disease worsening ([Perng et al., 2017](#)). With this unpredictable symptom profile, patients should be counseled to monitor their HS disease activity closely during pregnancy and to seek treatment if needed.

We found that 10 participants reported that a physician advised them to have a C-section over VD due to their severe anogenital HS, suggesting that a woman's delivery method can be affected by the presence of HS. Of note, more than half of our patients who underwent a C-section reported developing new HS lesions in the incision scar; therefore, patients who have a C-section should be counseled regarding this potential risk. More than a fifth of patients with anogenital disease who delivered vaginally reported that VD caused an HS flare. Thus, anticipatory counseling may be beneficial, although these patients may have experienced an HS flare after pregnancy regardless of the delivery method. Further

investigation is needed to explore whether the process of VD itself can trigger or contribute to flares. These results emphasize the importance of having dermatologists work closely with their obstetrics and gynecology counterparts to discuss optimal delivery methods as well as to counsel patients regarding the potential consequences of the planned delivery method on HS symptoms.

Menopause has previously been thought to be accompanied by a decline in disease severity (Kromann et al., 2014). The majority of our study participants reported that symptoms were more likely to be unchanged or worsen with menopause. Although the reason for this finding is unclear, one possible explanation could be that patients were older at the time of menopause and had a longer time to develop increased numbers of lesions in more anatomic regions; thus, the overall disease burden was thought to be higher with menopause. Nevertheless, this result suggests that long-term follow-up in patients with HS is important.

Study limitations include lack of respondent racial diversity and recall bias. There was also reliance on patient reporting of their Hurley stage by providing patients with descriptions of each stage, as well as patient reporting of their HS disease status, which may differ from objective clinical determinants of disease severity as well as disease improvement or worsening. In addition, we elicited survey responses from members of HS support groups on social media and from HS specialty clinics, which may not truly represent general HS population demographics. We did not distinguish between patients who received the survey link through an HS specialty clinic versus through social media. As with any anonymous, Web-based survey, participants could potentially complete the survey more than once. Despite these limitations, to our knowledge, this is the first study to report on delivery method and delivery-related healing complications in HS; thus, we believe this adds valuable information to the existing literature on HS in women.

Conclusion

Further investigation is required to elucidate the mechanistic link between HS disease activity and hormonal changes throughout menses, pregnancy, and menopause. Development of HS screening tools may facilitate earlier diagnosis, leading to earlier treatment and more adequate disease control during a woman's childbearing years. Multidisciplinary collaboration is essential in the development of individualized treatment plans for women of childbearing age with HS. Prospective studies (Adelekun et al., 2020) in women with HS are needed to further investigate the impact of delivery method on HS symptoms and improve dermatology and obstetrics/gynecology collaborative counseling of patients with HS regarding the optimal delivery method.

Conflict of Interest

None.

Financial Disclosures

Vivian Y. Shi is a stock shareholder of Learn Health and has served as an advisory board member, investigator, and/or received research funding from Sanofi Genzyme, Regeneron, AbbVie, Eli Lilly, Novartis, SUN Pharma, LEO Pharma, Pfizer, Menlo Therapeutics, Burt's Bees, GpSkin, Altus Labs, and Skin Actives Scientific. There were no incentives or transactions, financial or otherwise, relevant to this manuscript.

Funding

This research was supported by the National Institutes of Health National Center for Advancing Translational Science, University of California Los Angeles Clinical and Translational Science Institute (grant number UL1TR001881).

Study Approval

The author(s) confirm that any aspect of the work covered in this manuscript that has involved human patients has been conducted with the ethical approval of all relevant bodies.

Acknowledgements

The authors thank their patients and the members of the following HS support groups for completing the questionnaire: HOPE for HS, International Association of HS Network, and HS Warriors.

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