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Letter from the Editors

Shedding light on the impact of hidradenitis suppurativa on women and their families: A focus of the *International Journal of Women's Dermatology*

Hidradenitis suppurativa (HS) is a debilitating and disfiguring condition involving painful nodules, abscesses, sinus tracts, and scarring that is underrecognized in our communities. Unlike conditions such as acne, eczema, and psoriasis, this inflammatory condition is not as well known by patients and providers, and research and education in the area of HS is critical for both early detection and increasing the array of therapeutic options. A delayed diagnosis and historically poor response to treatment result in unnecessary suffering for patients with HS. Notably, this condition is most debilitating to women of childbearing age, and this burden is felt by both women and their families.

Within the *International Journal of Women's Dermatology*, we have attempted to shed light on this condition given that it afflicts women disproportionately and results in significant morbidity. The Women's Health Highlight in this January 2022 issue, developed by Frew et al., highlights issues germane to the female patient population, including its effect on intimacy, quality of life (QoL), work impairment, menses, pregnancy, and menopause (Frew et al., 2022). This health highlight builds on work previously published in the journal, including Dr. Gregor Jemec's article "Hidradentitis suppurativa and intimacy" and Hsiao et al.'s article "Gender differences in sexual health impairment in hidradenitis suppurativa: A systematic review", which both explored how women are negatively affected in their sexual relations as a result of disfigurement, active inflammation, sinus tracts, and scarring (Jemec, 2018, Yee et al., 2021). Similarly, Dr. Hsiao et al. explored gender differences in HS characteristics in a retrospective cohort of specialists with HS (Shih et al., 2021).

In fact, a primary focus of our journal has been to highlight how HS disproportionately affects women of childbearing age. According to Collier et al. (2020a), the annual incidence of HS in the United States is double that of men (12.1 per 100,000 women). Women not only more commonly have HS but face an additional set of unique challenges related to menstruation, pregnancy, and lactation. In another study focused on the characterization of perimenstrual HS flares, Collier et al. (2020b) found that 62.4% of women of childbearing age with HS reported flares with menses, typically occurring during the premenstrual period. Progestogen-only contraceptive drugs were found to worsen HS; however, combined oral contraceptive pills and spironolactone had better results. Nevertheless, these studies call for an improved understanding of the role of sex hormones and further investigation of treatment efficacy. Does hormonal HS warrant consideration as a subtype of HS? Fernandez et al. (2020) contributed significantly to this discussion by characterizing HS in female patients in various stages of life. The study revealed that menstruation caused worsening of HS symptoms in 76.7% patients, pregnancy had mixed effects, and menopause typically caused no change or worsening of HS symptoms. This study also showed that HS may affect delivery methods, because physicians reportedly advised patients with severe anogenital HS to have Cesarean sections as opposed to vaginal deliveries (Fernandez et. al, 2020). However, more than half of patients who had Cesarean sections reported new HS lesions in the incision scar Collier et al., 2021. Thus, women of childbearing age with HS will be better served by anticipatory counseling and further investigation to explore the consequences of delivery methods. In this vein, Collier et al. (2020a) examined provider perspectives on the management of HS during pregnancy through a survey study recently published as well.

It is critical to address the lack of recognition of and education regarding HS that contributes to the delay in diagnosis. In a recent case report, Drs. Monica Shah, Muskaan Sachdeva, and Afsaneh Alavi described the struggles of a 33-year-old female patient after a 7-year diagnostic delay (Shah et al., 2020). This patient is not alone. A multinational study reported that the mean diagnostic delay for HS is 10.2 years (Wright et al., 2021). The authors bring to light the predicament of patients with HS who may be hesitant to visit a clinic due to embarrassment over lesions in intimate areas or malodorous discharge from lesions. Furthermore, patients experience further disease progression when not diagnosed expeditiously owing to the lack of confirmatory diagnostic testing, unclear understanding of the pathophysiology, and the absence of a common, widely used layman's term for the condition.

With the burden of treatment falling in the lap of clinical management, Drs. Emily Nesbitt Stephanie Clements and Marcia Driscoll compiled an all-encompassing guide for clinicians for determining treatments based on Hurley stage, recommending mostly antibiotic therapy for initial stages and for biologic treatments and surgical procedures later stages (e.g., deroofing; Nesbitt et al., 2020). Deciding which antibiotics are optimal for specific patients can often present a conundrum for dermatologists. Many treatments, such as methotrexate, are promising due to their ability to prevent neutrophil chemotaxis and inhibit inflammatory markers, such as NF-kB and IL-17. Savage et al. (2020) conducted a chart review that revealed that patients using methotrexate as their primary therapy demonstrated some reductions in HS Physi-

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cian Global Assessment score, inflammatory nodule count, and abscess count.

Given that HS not only affects the skin, special efforts have been made to better understand the immune effects on other organ systems and potential comorbidities. In their review article, Cartron and Driscoll (2019) found metabolic and cardiovascular comorbidities to be most commonly associated with HS. Similarly, in a retrospective cohort study, Parameswaran et al. (2021) found that patients with HS were significantly more likely to have a diagnosis of anemia, with the most common subtypes being anemia of chronic disease, iron deficiency anemia, and sickle cell anemia. In addition to treating the symptoms of HS, dermatologists should also be aware of such associations to facilitate appropriate screening and referral for integrated management.

However, the extent of comorbidities associated with HS stretches beyond the physical realm. For example, in a study about the QoL and sexual health of patients with HS, Alavi et al. (2018) found that most patients with HS reported having a sexual partner. Furthermore, regardless of whether lesions were present in the genital areas, HS was found to impair sexual functioning. Notably, patients with HS scored significantly lower on depression and anxiety indices, both of which were correlated with impaired sexual health. These data invite more attention to psychological comorbidities and highlight the role of provider empathy, the need to connect patients with psychological and counseling networks, and the opportunity for further studies to examine the correlation between HS, sexual functioning, and QoL.

Delving deeper into the impact of HS on QoL, Storer et al. (2018) surveyed patients with HS and obesity. This study revealed that the psychological burden of skin disease outweighed that of obesity. Specifically, patients with HS expressed a willingness to forfeit more years of life to live free of skin disease in comparison with the years of life they would give up to live at a normal weight. In addition to shedding light on the morbidity of HS, this study suggested the value of an integrative approach to skin disease and obesity.

Touhouche et al. (2020) echoed this sentiment in a study that demonstrated both the importance and practical challenges of an integrative approach to treating HS. In their retrospective study, high patient satisfaction ratings were associated with an integrated multidisciplinary care model, including examinations by dermatologists, plastic surgeons, smoking specialists, and nutritionists. However, the most significant challenge to this model by far was adherence to long-term, multidisciplinary care in comparison with a short-term clinical intervention, such as surgery. Similarly, Jemec (2020) explored the importance of multidisciplinary care in his paper "Multimodal management of hidradenitis suppurativa".

The stigma of HS due to painful lesions, odorous discharges, and presence in intimate areas can be a cause of isolation, anxiety, and depression. In the era of COVID-19, identifying well-established counseling networks and support groups can often be a challenge. Indeed, the pandemic can accentuate harmful impacts of HS on QoL and mental health. As a result, virtual support groups, such as the one initiated and described by Stout et al. (2020), can help patients with HS to cultivate mutual relationships and express their sentiments in a space that is safe and supportive. This structure may also be beneficial to patients with other chronic or inflammatory skin diseases as the repercussions of the pandemic persist. Shukla et al. (2020) similarly explored how patients with HS can be engaged through their publication "Quality and engagement of online hidradenitis suppurativa information."

This collection of publications in the *International Journal of Women's Dermatology* allows us to reflect on the recent progress in treating HS, as well as the challenges that persist. We are enthusiastic about ongoing studies to identify reliable biologic treatments, especially for patients with Hurley stage II and III disease. We hope that the unclear pathophysiology of HS will be a call to action for further studies to better understand the potential role of genetics, the immune system, and tissue molecular mechanisms in contributing to the disease. We hope that the recognition of detriments to QoL and psychological morbidities will prompt more empathy, integrative management, and robust support group networking. Finally, we realize that HS is an issue that disproportionately affects women—specifically, Black women, in whom HS is the most prevalent. Thus, we recognize the importance of improved care and support for our skin-of-color populations in particular. Please join us in spreading the word about this debilitating condition to colleagues, patients, families, and friends to increase HS awareness, particularly given that this condition disproportionately affects both female and skin-of-color patients throughout the world.

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