Hidradenitis suppurativa patient perspectives during the COVID-19 pandemic

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To the Editor:

Hidradenitis suppurativa (HS) is a debilitating inflammatory condition that often requires complex management. The impact of the coronavirus disease 2019 (COVID-19) pandemic on HS patients remains unknown. This study examines the influence of COVID-19 on HS care by evaluating patients' perceived access and quality of care, telehealth utilization, lifestyle, and treatment changes.

An anonymous questionnaire was distributed via HS support group Facebooks pages in May 2020. The study was exempted by the University of Arizona Institutional Review Board. Respondents self-reported Hurley staging using a provided description. Associations between patient characteristics and Likert scale questions were assessed using Spearman correlation coefficient. Statistical analyses were performed using IBM SPSS V25 (Armonk, NY) and P values less than 0.05 were considered statistically significant.

A total of 335 respondents participated (mean age ±SD, 37.4±10.0 years; 326 female participants [97.3%], 9 male participants [2.7%]), (**Table 1**). The average body mass index of respondents was 36.7 (SD 10.5). The majority of respondents were from the United States (N=239, 72.0%) followed by the United Kingdom (N=40, 12.0%), and Canada (N=27, 8.1%). The majority of respondents were White/Caucasian (N=240, 71.6%) followed by Hispanic/Latino (N=34, 10.1%), and Black/African descent (N=30, 9.0%). The most reported Hurley stage was moderate (N=181, 54.2%), followed by severe (N=132, 39.5%), and mild (N=21, 6.3%).

Only four respondents (1.2%) formally tested positive for COVID-19. Over a third (N=122, 36.4%) reported current tobacco use, of which 18 (14.8%) reported a decrease in tobacco use, 28 (23.0%) reported an increase, and 76 (62.3%) reported no change. Among respondents who receive injectable medications for their HS, nine (9/80, 11.3%) stopped using their medication because of concerns over COVID-19. Only three respondents (3/120, 2.5%) among those receiving an oral medication other than oral antibiotics for their HS reported stopping their medication because of concerns over COVID-19. More than half of respondents (51.2%, 171/334) avoided the emergency room/urgent care for HS flares since the pandemic began. The majority (58.2%, 160/275) agreed that they were able to reach a dermatologist during the pandemic (**Figure 1**). Nearly half (49.2%, 150/305) were concerned that HS would increase risk for COVID-19.

Respondents with higher Hurley stages are significantly more likely to disagree that their concerns have been adequately addressed during the pandemic by their dermatologist (ρ=-0.17, P=0.002) and that telemedicine and in-person visits are equally effective (ρ=-0.14, P=0.013), but are significantly less likely to express concern that their

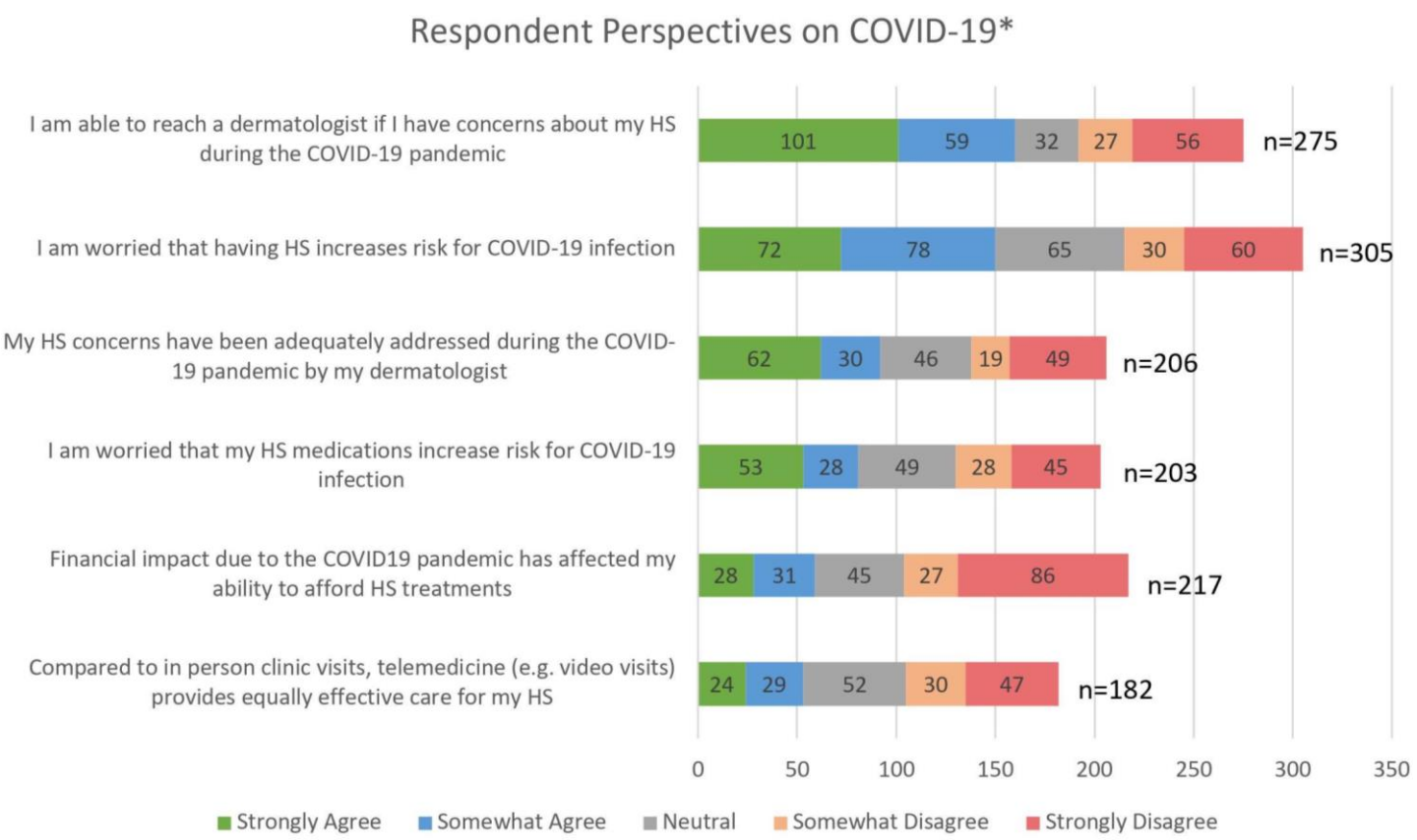

Figure 1. *Respondents' perspectives on hidradenitis suppurativa care and concerns during the COVID-19 pandemic.*

HS medication would increase risk for COVID-19 (ρ= -0.14, P=0.010). Higher Hurley stage did not significantly associate with flare frequency during the pandemic. Age and race/ethnicity did not significantly correlate with flare frequency or perceptions regarding HS care during COVID-19.

The majority of the respondents (61.2%, 205/335) reported increased HS flares, which may be related to reported weight gain, increased smoking, and financial stress (**Figure 1**). Most patients on HS injection (88.8%, 71/80) and oral (97.5%, 117/120) medication have continued their treatment during the pandemic. Overall, 42.3% (77/182) of respondents disagreed that telemedicine provides equally effective care.

The pandemic has impacted important aspects of HS care. Providers should focus on understanding and meeting unique patient needs both through telemedicine and in-person visits. Kang et al. recommends strategies for remote HS management, including methods for optimizing teledermatology visits, educating patients on strategies for minimizing flares, and designing individualized treatment regimens [1]. Cohen et al. recommended a virtual "rooming" process and providing login-in instructions for patients prior to telemedicine visit [2].

As the pandemic continues, COVID-19 registries may help shed light on the safety of continuing immunosuppressants and immunomodulators during COVID-19. Recent studies have not reported an increased risk in COVID-19 related hospital admission, intensive care unit admission, or severe infection among HS patients, including those who receive systemic therapies; however, these studies are limited by small sample sizes [3-5]. Confirmed COVID-19 in HS patients can be reported to the Global HS COVID-19 registry [6,7] and the American Academy of Dermatology COVID-19 registry [8].

Limitations to this study include self-reported Hurley staging and lack of generalizability of respondents on Facebook to the general HS population. The detailed geographic distribution of patients is unknown and may influence a participant's

perspective on the access and quality of HS care during the pandemic. Future public health and epidemiologic studies are needed to further evaluate the direct impact of COVID-19 on dermatology practice closure and HS care across the globe.

As the COVID-19 pandemic continues, it is important to continue to assess the impact of COVID-19 on HS patients. With remote management continuing in many clinics, emphasizing methods for improved telehealth care can further optimize care for HS patients during this challenging time.

Potential conflicts of interest

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. KNP, EKC, TRG, and JLH have no conflicts of interest to declare.

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Table 1. *Respondent demographic information.*

Patient Characteristics (N=335)*	Mean (SD), range min-max	
Age at time of survey completion (years)	37.4 (SD=10.0), min=18.0, max=64.0	
BMI[#]	36.7 (SD=10.5), min=18.2, max=64.6	
Gender	**N**	**%**
Female	326	97.3%
Male	9	2.7%
Country of residence (missing 3)		
United States	239	72.0%
United Kingdom	40	12.0%
Canada	27	8.1%
Other[§]	16	4.8%
Australia	10	3.0%
Race/Ethnicity		
White/Caucasian	240	71.6%
Hispanic/Latino	34	10.1%
Black/African descent	30	9.0%
Mixed or Multi-racial	17	5.1%
Asian/Pacific Islander	7	2.1%
Other	7	2.1%
HS Severity[#]		
Mild (Hurley Stage 1)	21	6.3%
Moderate (Hurley Stage 2)	181	54.2%
Severe (Hurley Stage 3)	132	39.5%
I have been formally tested positive for COVID-19:		
No	331	98.8%
Yes	4	1.2%
Do you currently use tobacco?		
No	213	63.6%
Yes	122	36.4%
How has your tobacco use changed as a result of COVID-19? (N=122)		
Decreased	18	14.8%
Increased	28	23.0%
No change	76	62.3%
My injection medication for HS has been stopped because of concerns over COVID-19. (N=80)		
No	71	88.8%
Yes	9	11.3%
My oral medication for HS has been stopped because of concerns over COVID-19 (N=120)[†]		
No	117	97.5%
Yes	3	2.5%
Have you avoided going to the emergency room/urgent care for HS flares since the start of the COVID-19 pandemic?[#]		
No	163	48.8%
Yes	171	51.2%
Has your HS been flaring more frequently since the start of the COVID-19 pandemic?		
No	130	38.8%
Yes	205	61.2%
Have you experienced weight gain as a result of the COVID-19 pandemic?		
No	190	56.7%
Yes	145	43.3%

*Percentages were computed using complete data for each variable, for variables with missing data, total missing values are noted.
[#]Missing 1 respondent.
[§]Other includes two respondents (0.6%) from India and Malaysia and one respondent (0.3%) from Colombia, Poland, Italy, Sweden, Ireland, Croatia, Iceland, the Netherlands, Philippines, New Zealand, "Africa", and one not reported.
[†]Oral antibiotics were excluded.