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Editorial

The role of virtual support groups for patients with hidradenitis suppurativa during the COVID-19 pandemic



People with hidradenitis suppurativa (HS) experience significant social isolation because they have a disease that prevents them from working in person, traveling long distances, and engaging in intimate relationships (Keary et al., 2019; MacMahon et al., 2020). Long before the COVID-19 pandemic, these patients were socially distancing. Many of us have experienced overwhelming disruption and stress in our daily lives in the wake of the coronavirus pandemic, but patients with HS face a daily unpredictable struggle with pain, drainage, odor, and psychosocial suffering. Virtual support groups can provide much-needed social connection, and physicians and trainees can initiate them. On the evening of March 31, 2020, a group of three patients struggling with severe HS, accompanied by facilitators, congregated over a live video conference to lament a disease that has affected their lives to an even greater extent than the global pandemic.

Our research team spent months planning a focus group study to identify unmet needs for patients with HS. As the coronavirus pandemic started tightening its grip on Chicago, we thought proactively about how our study could adapt to a society where large group gatherings were now punishable by fine. We invited participants via the e-mail addresses they provided in our medical record system, as afforded by our institutional review board–approved protocol, 2 weeks in advance of the scheduled meeting. We attached consent forms and a study information handout.

Participants joined the group using a Zoom Video Communications account through Northwestern University. The discussion was semi-structured, beginning with introductions, but the content of the discussion was principally patient directed. Each participant was able to see, speak with, and react to other participants in real time. No one experienced technical difficulties that prohibited joining the meeting. Although the majority of patients elected to show their faces via webcam, those who deferred were still active discussants.

Despite the physical distance, members confided in each other with a profound level of social closeness. “Personally, I don’t really talk about it—the only two people in my life that even know I have HS are my wife and my brother,” reported one participant within minutes of joining the discussion. Over the course of the hour-long conference, the participants freely discussed diverse topics. Many were concerned about their susceptibility to COVID-19 with current biologic use, and all agreed on the silver lining of working from home; it makes coping with the pain and frequent care required of HS more manageable.

The participants discussed robust participation on social media platform groups on Facebook and Instagram, as well as WhatsApp group chats with global membership. Patients with HS have seemingly been ahead of the virtual social movement; studies demonstrate that these patients obtain information about symptoms, home remedies, and prescription treatments online, even before a formal diagnosis by a dermatologist (Cole et al., 2019; Hessam et al., 2017). Although patients with dermatologic conditions certainly subscribe to support groups online, the use of live video support groups in this population is not well defined and may revolutionize how support groups are held in the future.

In addition to HS, other groups of patients with documented socially isolating dermatologic diseases include those with Bechet’s syndrome, cutaneous lupus erythematosus, facial port wine birthmarks, and atopic dermatitis. These patients may benefit greatly from similar virtual support groups (Ogunsanya et al., 2018; Ozguler et al., 2019; Vivar and Kruse, 2018). A nondisclosure agreement signed by all participants prior to the meeting can protect confidentiality when groups are not held as part of an institutional review board–approved study with a formal consent form. In a time of widespread subscription to physical distancing, our patients with morbid dermatologic diseases may benefit immensely from live video conferencing support groups, and I encourage any dermatologist or trainee to facilitate one.

Disclaimer

The views expressed in the submitted article are the author’s own and not an official position of the institution.

Conflict of Interest

No conflict of interest.

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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.

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