

RESEARCH LETTER

Support Group Utilization and Perspectives Among Hidradenitis Suppurativa Patients

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ABSTRACT

Introduction: Hidradenitis suppurativa (HS) is a chronic inflammatory dermatosis associated with significant psychosocial burden. HS patients are more likely to experience mental health comorbidities such as depression and anxiety. They may also experience isolation due to fear of stigmatization as HS lesions are often associated with pain, scarring, and odor. This study investigates the perspectives of HS patients on HS support groups and the usage of this resource among this population.

Methods: An anonymous Redcap survey was utilized via online social media HS support groups between 10/2021-1/2022 to collect demographic, usage, and perspective data. Comparative statistics were conducted and p-value of <0.05 was considered significant.

Results: Of the 166 respondents, 78% respondents were part of an HS support group however, only 12% of respondents were recommended to join by their main HS healthcare provider and most (68%) learned about support groups through their own internet searches. Most respondents were daily (42%) and weekly (38%) support group users. Virtual meetings were preferred by the majority compared to in person meetings (50% vs 13%). The top reasons respondents reported attending support groups were to better understand HS, increasing their knowledge of HS resources, and access to treatment/care tips. Respondents without dermatologists as their main HCP and skin of color (SOC) respondents were more likely to report that support groups improved their care of HS (4.29 vs 3.90, p=0.031).

Conclusion: Our findings highlight the preferential format of virtual support groups and that support groups may be an underutilized resource by healthcare providers for their patients. Support groups may help to narrow gaps in education when patients are unable to access or have delays in obtaining dermatological care, especially in SOC patients who have historically experienced higher rates of healthcare disparities.

INTRODUCTION

Hidradenitis suppurativa (HS) is a chronic inflammatory dermatosis with significant physical, social, and emotional burden.¹ HS patients may have higher odds of having depression and anxiety.² They may also experience isolation due to fear of stigmatization with pain, scarring, and odor.^{3,4} HS support groups serve as a resource to support mental health for HS patients. Learning about specific preferences from patients may help tailor support group recommendations. Herein, we aim to learn about HS patient support group use and perspectives.

METHODS

An anonymous Redcap survey was distributed through online social media HS support groups between 10/2021-1/2022. Data regarding demographics, use, and perspectives of HS support groups was collected. Comparative statistics were completed and differences in perspectives were analyzed based on the respondent's age, gender, race, HS severity, and the type of healthcare provider (HCP) they see for HS. A p-value of <0.05 was considered significant.

RESULTS

The majority of the 196 respondents were female (92%, 180/196) and White (75%, 147/196). A dermatologist was the primary HCP for HS in 65% (128/196) of patients. 12% (23/196) were seen at an HS specialty clinic. Out of 166 respondents, 78.3% (130/166) were in a HS support group and 73.8% had joined for 2 years or less (96/130). Only 12% (20/166) were recommended to

join a support group by their main HCP, with most respondents learning about support groups through internet searches (68.7%, 114/166). Most respondents utilized their support groups daily (41.5%, 54/130) and weekly (37.7%, 49/130). Most respondents preferred virtual meetings over in person meetings (50%, 81/162 vs 13%, 21/162). (Figure 1)

The top three reasons that respondents reported going to a support group were to better understand HS (79%, 130/164), learn about available resources (79%, 130/164), and gain access to treatment and care tips (77%, 127/164) (Figure 2). Close to half of respondents reported a difference between the information they receive from HCPs vs support group regarding HS causes (46%, 75/162) and HS treatments (52%, 84/162).

Compared to respondents with dermatologists as their main HS HCP, those without were more likely to report support groups improve their care of HS (4.24 vs 3.86, $p=0.049$) and noted a difference in information about HS causes (3.89 vs 3.24, $p=0.005$) that they receive from their HCP vs support groups. Skin of color (SOC) respondents were significantly more likely to agree that support groups improve their care of HS (4.29 vs 3.90, $p=0.031$) and increases their knowledge of available HS resources (4.68 vs 4.37, $p=0.02$) vs non-SOC respondents.

DISCUSSION

Our results highlight the positive impact that HS support groups have in HS education. With increasing awareness of HS, support group use has increased over the past two years. Virtual support groups may be the preferred format due to scheduling flexibility, ease of attendance, and physical comfort.

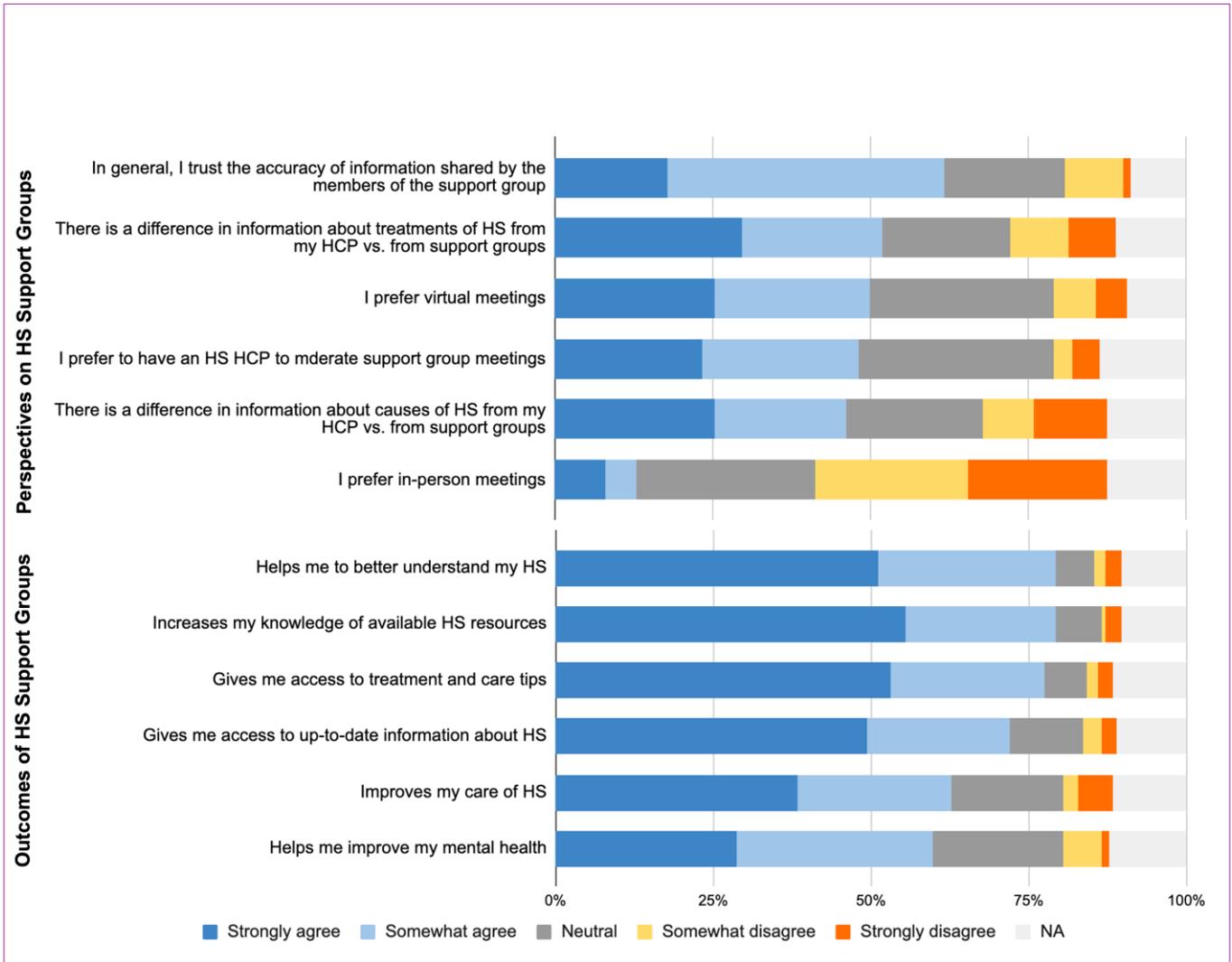


Figure 1. Respondent reported perspectives and outcomes on HS support groups

Most respondents trust the information provided in support groups, but also find differences in information provided by their HCP's and support group.

Respondents without dermatologists and SOC respondents were more likely to report that support groups improved their care of HS. Historically, SOC patients have experienced healthcare disparities and may lack access to specialist care for HS. Thus, support groups may narrow gaps in education when patients are unable to access or have delays in obtaining dermatological care.⁵ The results show HCP's may be underutilizing HS support groups as a recommended resource. HCP's can recommend support groups to address emotional health in addition to other mental health referrals.

Study limitations include self-reported HS disease severity and female-predominant responses, limiting generalizability. Ultimately HCP's, support groups, and researchers should work alongside each other to continue advocacy efforts, raise awareness about HS, and reduce gaps in care.

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