

Understanding the Impact of Stigma in an Online Community of Hidradenitis Suppurativa Patients

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PLAIN LANGUAGE SUMMARY

WHY WAS THIS STUDY NEEDED:

People with hidradenitis suppurativa (HS) often feel stigmatized. This means they have bad feelings about having HS, like feeling shame. By asking people with HS to take this survey, we tried to learn more about where these feelings come from and how these feelings affect people with HS.

WHAT DID THIS STUDY SHOW:

People with HS feel stigma, which arises from their own feelings and from perceived or actual actions by other people such as friends, partners, co-workers, and doctors/health care providers. People who have these feelings are more likely to be anxious, depressed, or feel ashamed.

WHY THIS IS IMPORTANT:

We hope to learn what makes people with HS feel this way about themselves or what others do that make them feel this way. If we can learn this, we can come up with ways to better help people with HS.

BACKGROUND

People with hidradenitis suppurativa (HS) often experience feelings of stigma.¹ This study aimed to assess how they feel about the impact of HS on their sense of self and how they think others perceive them.

OBJECTIVES

1. To evaluate sources of stigma in HS.
2. To evaluate the dynamics and impact of internal and external stigma in HS.



SHSA 2024

ACKNOWLEDGEMENTS:

This study was conducted by MyHealthTeam, funded by UCB Pharma. The HS PtGA and ISBQv2 series were licensed from Penn State Research Foundation. Additional thanks to Joslyn S Kirby, MD, MS, MEd and Melissa Butt, DrPH for their assistance.

REFERENCES:

¹Singh, R, et al. Arch Dermatol Res. 2023 May;315(4):1049-1052. doi: 10.1007/s00403-022-02412-5.

METHODS

A 36-item electronic cross-sectional survey was administered in May 2023 with members of an online social network for people living with HS, myHSTeam. Inclusion criteria included age ≥ 21 years, prior diagnosis of HS, and ≥ 1 HS lesion in the past 6 months. Descriptive statistics were used to summarize survey results. Significant differences noted at $p < .05$ (2-sample t test).

Externally validated instruments in the survey included the HS Patient Global Assessment (PtGA); the Numerical Rating Scale (NRS) for pain, Generalized Anxiety Disorder questionnaire (GAD-7) and the Patient Health Questionnaire (PHQ-9) for depression. Additionally, the survey included questions from the Internalized Skin Bias Questionnaire (ISBQv2).

RESULTS

Among 350 respondents, most reported having Hurley Stage II (44%) or Hurley Stage III (39%). Additionally, 61% are in the US, 26% UK, and 13% other countries. 86% female, 13% male, 1% other. Mean age is 47 years and mean age at onset is 24.5 years. In the US (216), 58% are White, 25% Black, and 10% Hispanic/Latino. In the UK (91), 96% are White British.

294 respondents (84%) reported that they themselves or someone else has made them feel self-conscious or ashamed about their HS. Additionally, 49% reported that in the previous year, they felt hassled, made to feel inferior, or discriminated against in at least one of the following circumstances: during a relationship, a social interaction, medical care, or at work/school (faced external bias). (Figure 1)

Respondents who faced external bias were significantly more likely to say HS negatively affected different aspects of daily life (intimacy, socializing, leaving home, going to work or school, or seeking medical care) in the past three months compared to those who had not experienced bias. (Figure 2)

Those who faced external bias also were significantly more likely to experience internalized stigma than those who had not experienced external bias. Respondents rated their level of agreement on a series of statements about the impact of HS. These statements included whether they felt like they could be their “true self” with HS, anxiety about what people might think of them, as well as their sense of shame and depression. (Figure 3)

CONCLUSIONS

Patients with HS frequently experience internal and external stigma. Those who experience external bias have worsened quality of life, self-esteem, and mental health. Understanding these associations may guide HCP-patient communication during appointments and influence interventions to improve care.

FIGURE 1. Percent Who Felt External Bias in the Past Year and Qualitative Examples of How They Described the Experience

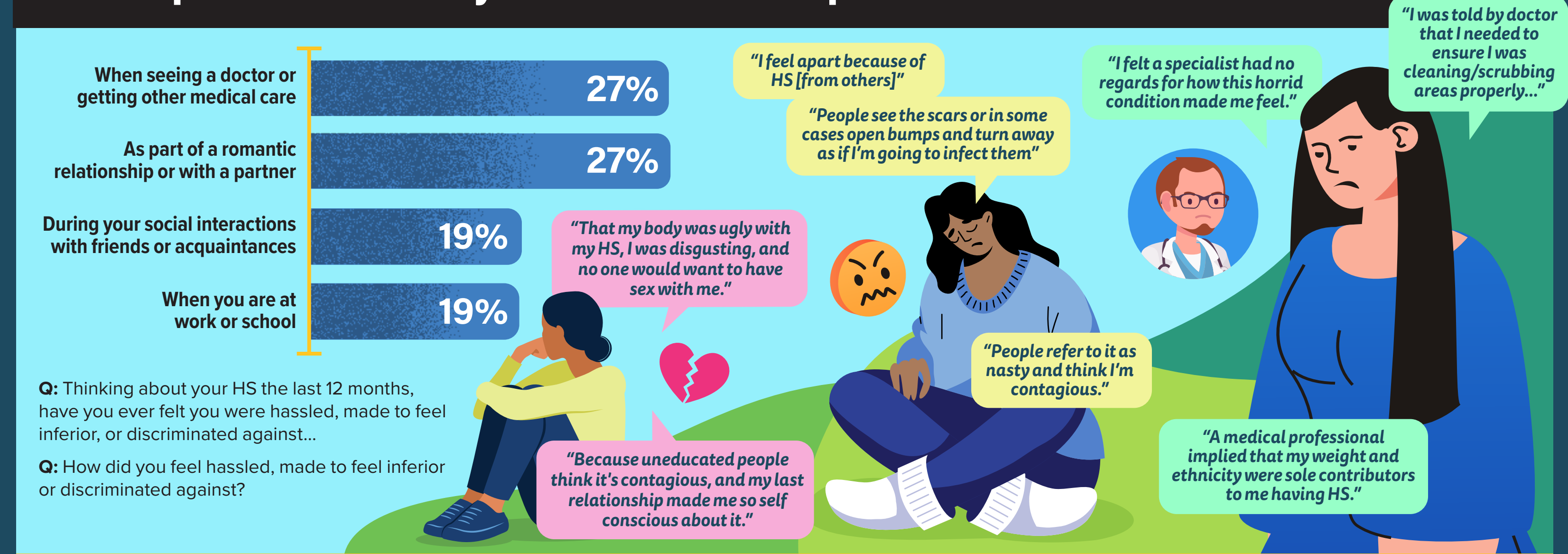


FIGURE 2. Impact of HS on Daily Living Over the Past 3 Months Those Who Have Faced External Bias vs. Those Who Have Not

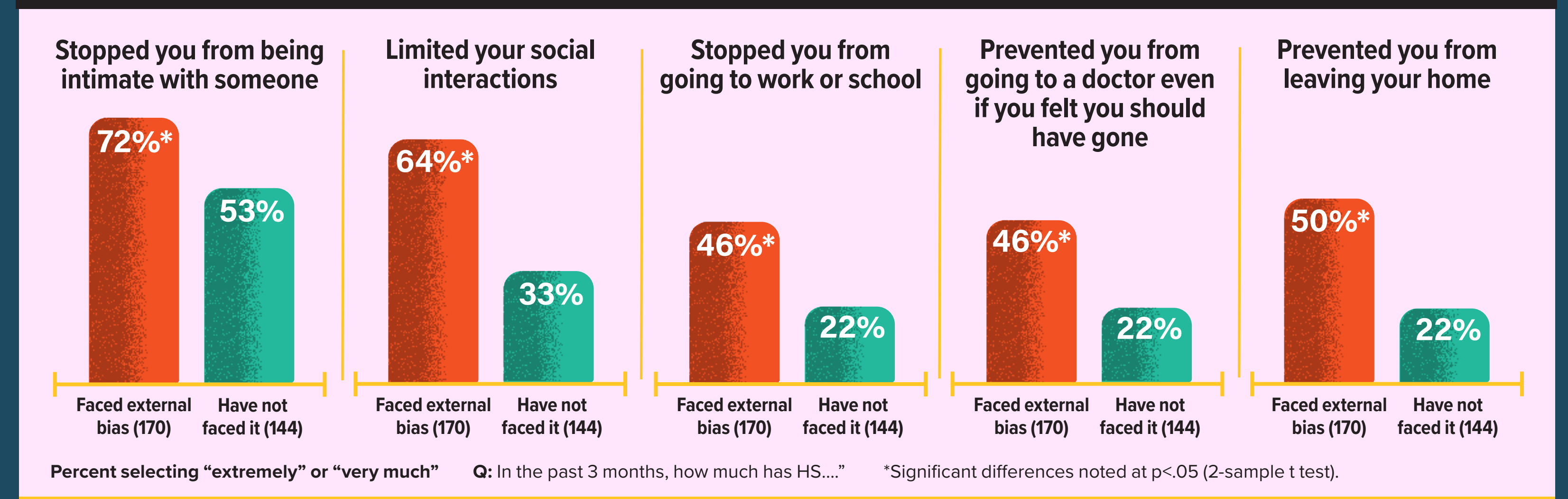


FIGURE 3. Internalized Skin Bias, Self-Worth, and Emotional State Those Who Have Faced External Bias vs. Those Who Have Not

