Scarred for Life:

2020 Update

A NATIONAL REPORT OF PATIENTS' EXPERIENCES LIVING WITH HIDRADENITIS SUPPURATIVA

Executive Summary and Recommendations

May 2020

EXECUTIVE SUMMARY

Hidradenitis suppurativa (HS) is a chronic and devastating skin condition, characterized by painful and recurrent boils and abscesses in skin folds, including the axillae, under the breasts, lower abdomen, groin, genital area and buttocks. This dermatological disease results in pain, purulent discharge and foul-smelling odor. Affecting up to 4% of Canadians, the physical and psychosocial impacts of HS are tremendous, and no cure exists.

"I feel like the system failed me. For years I was told my symptoms were because I was fat, or didn't shower enough, or was using the wrong products for my body. I ended up hiding my symptoms, lying to my parents, and suffering for 20 years."

In 2017, the Canadian Skin Patient Alliance, a not-for-profit patient organization formed to help Canadians with skin disorders, collaborated with the physician organization Canadian HS Foundation and patient group HS Aware, on a comprehensive examination of the patient experience with HS. Together, we developed the Hidradenitis Suppurativa Patient Experience (HSPE) Survey, with the goal of providing a baseline measure for the state of care for individuals with HS. This online survey was completed by 167 individuals with HS (30% from Canada and 70% from the United States). Results demonstrated that respondents were very dissatisfied with the care provided by their healthcare systems en route to diagnosis, involving an average of 9 years and numerous appointments with healthcare providers (HCPs), misdiagnoses and failed treatments. Although patients tried multiple medical and natural treatments, as well as lifestyle modifications, to prevent or treat their HS symptoms, most offered little to no improvement. Many individuals had moderate pain on a daily basis, and struggled with managing symptoms and coping with depression and anxiety.

Based on survey findings, we made several recommendations to Canada's healthcare system to increase awareness and education of HS among HCPs, provide funding for new and effective treatments, and link patients to resources and social support to help with pain management and the psychosocial impact of HS.

In January 2020, our team conducted the survey again to identify if progress had been made in improving the diagnostic odyssey, and in the ongoing care and treatment for those with HS. For this update, all individuals with HS were eligible to participate, regardless of geographical location. A total of 537 surveys were received, of which 73 were from Canada. The average age was 38 years with a range of 14 to 73 years.

Median time from symptom onset to HS diagnosis was 7 years for respondents in Canada, considerably shorter than the 9 years reported in 2017. During this pre-diagnosis period, 97% of respondents visited a family physician or walk-in clinic doctor regarding symptoms, and 48% made 10 more visits (53% in 2017). More than half made at least one trip to the ER, and 16% visited the emergency room (ER) 10 or more times (nearly half of the 30% who reported doing so in 2017). Sixty-two percent visited a dermatologist at least once (down slightly from 72% in 2017) and 10% made at least 10 visits to dermatologists (also less than the 2017 finding of 17%). Of the Canadian respondents, 83% received at least 1 misdiagnosis (a slight increase from the 78% who reported this being their outcome in 2017), and they received an average of 3 misdiagnoses before their care team identified HS. Similar to the results of our 2017 survey, dermatologists were the HCPs that most commonly made the HS diagnosis in Canada, followed by family physicians.

Only 24% of respondents reported satisfaction with the healthcare system during the pre-diagnosis period, rising to 41% when asked about current satisfaction with the system. We also observed this incline in 2017, where only 20% reported being satisfied pre-diagnosis to 43% being satisfied with their then-current level of care.

Survey respondents, regardless of country, had tried an average of 15 different medications, home treatments, surgical procedures and lifestyle modifications to manage their HS symptoms. However, only a few found that these changes offered significant improvement. Maintaining low stress levels and dietary changes have been most successful, as was non-incision and drainage surgical treatment. Biologics were used by 27% of respondents, of which 38% found a significant improvement in symptoms. Long-course antibiotics were more commonly tried (82% of respondents) but only 11% reported a significant improvement from their use.

Respondents reported that their main treatment goals were to control HS symptoms, cure HS completely and be able to enjoy social activities. However, only 13% were satisfied with the ability of currently available treatments and therapies to meet such goals. It is evident that there is much room for improvement in terms of providing safe, effective and accessible treatments to individuals with HS that will allow them to manage both the physical and emotional aspects of this condition.

Access to promising treatments was often blocked by obstacles such as respondents' healthcare providers not feeling it was worth trying until other options or lifestyle changes (such as weight loss and smoking cessation) were exhausted. As a result, many patients felt forced to fight for access to new medications while being kept on problematic short-term medications such as antibiotics. Respondents also felt that potentially effective options such as biologics or even more conventional options (such as laser hair removal) were not covered and therefore not affordable.

We asked respondents from Canada about their monthly HS-related expenses, and found that 68% did not have a private insurance plan that covered any of their costs. Regardless of insurance coverage, respondents were paying at least $65 every month on non-biologics prescription drugs and non-prescription items (soaps, bath products, creams, wound care, non-prescription treatments/therapies, etc.).

The impacts of HS on those who live with the disease are massive. More than 4 out of 5 respondents reported that their condition had a negative impact on their work performance, their social lives, and their ability to be intimate with a partner. Encouragingly, there was an increase in the percentage of those who had a HCP helping to control this symptom from 44% in 2017 to 51% in 2020, which indicates that more HCPs are recognizing the painful aspects of the disease. However, since nearly half indicated that their pain was not controlled, it is not surprising that in addition to struggling with managing symptoms and low physician awareness of HS, nearly 7 out of 10 respondents were suffering from feelings of depression.

Diagnoses are being made more quickly than previously reported in 2017 – which may reflect greater physician awareness – though patients are still frustrated by the lack of support for their condition, the lack of effective treatment options for the physical manifestations of HS, and the psychosocial impacts of the visible nature of their symptoms. While some patients feel supported by their HS healthcare team, others are struggling with the tiresome practice of continuously having to educate their HCPs and advocate for their own health and access to medications during HCP visits. Patients around the world are forced to balance the management of their devastating symptoms, weighing the risks and benefits of every new treatment and therapy, and handling the pervasive and debilitating effects of this condition on their lives.

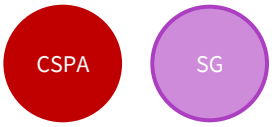
RECOMMENDATIONS

Based on the results of our update, we have developed several recommendations to improve the lives of individuals with HS, and have designated which government bodies, organizations and groups* would be involved with the implementation of each one.

I. RAISING AWARENESS ABOUT HS TO SUPPORT QUICKER & MORE ACCURATE DIAGNOSES

1. Increase HS awareness for healthcare providers who are most likely to see a person living with HS. Time to diagnosis for future patients could be reduced by providing educational sessions and toolkits to dermatologists, gynecologists, family physicians, ER physicians, surgeons, infectious disease specialists, wound care teams, and dermatology nurses. This information should include hallmarks of HS, diseases for which HS is often mistaken or misdiagnosed, associated comorbidities, best practices to screen HS patients for other concurrent diseases, and treatment options.

2. Educate those who frequently provide services to people living with HS. Estheticians and other service workers are often sought out to manage some of the manifestations of HS. Targeted information should be developed to help educate people about HS, and how to access physician and specialist care.



3. All education should be rooted in anti-stigma practices. It is essential that healthcare providers and service providers understand the devastating psychosocial impact of the symptoms, and the need for compassion and sensitivity in interactions.

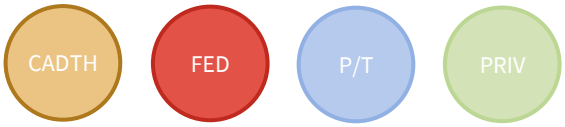
II. ENSURING PATIENT ACCESS TO DIAGNOSTIC TOOLS AND COLLABORATIVE CARE

4. Develop a coordinated, multi-disciplinary approach for managing HS among various healthcare providers to provide optimal care. Patients with HS often see multiple healthcare providers and it can be challenging to ensure that care is cohesive and optimized. Collaborative care should be patient-centred and include management strategies for both the physical and emotional symptoms associated with this disease.

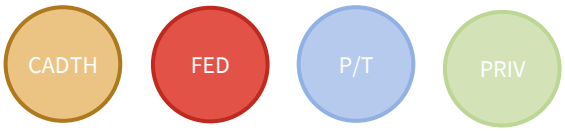
5. Expedite access to procedures. Those that are suffering from emergent symptoms involving discharge and excruciating pain should be able to access office-based procedures and surgical interventions (including those requiring operating room time) in a timely manner.

III. SUPPORTING PATIENT ACCESS TO SAFE, EFFECTIVE AND AFFORDABLE TREATMENTS TO MANAGE HS SYMPTOMS

6. Expedite funding decisions for new treatments for HS which are safe and effective. Individuals with HS have attempted numerous treatments and therapies to manage their debilitating symptoms. There remains a need for additional treatment options. Access to new and promising treatment is critical to helping patients gain a sense of control over their disease and begin to regain their quality of life.



7. Increase insurance coverage and financial assistance for proven treatments and procedures. The nature of this disease requires ongoing care and a constellation of different approaches. Individuals with HS incur considerable expenses on HS-related items, including those required for daily wound care. More than 8 out of 10 individuals use both prescription medications, including biologic drugs, and other procedures such as laser hair removal or home treatments, which can provide symptom relief for individuals with HS.



IV. INCLUDE STRATEGIES TO MANAGE THE IMPACTS OF HS ON DAILY LIFE IN COMPREHENSIVE CARE PLANS

8. Evaluate every patient with HS for depression and offer support, care and referral to a specialist, when appropriate. The recently published North American clinical management guidelines for HS recognize the importance of screening people living with HS for anxiety and depression.[1] It is crucial that the psychosocial aspects of HS be recognized and supported as early as possible.

9. Integrate a pain management discussion into every interaction with patients with HS. People with HS are experiencing pain on a daily basis, making it very important to create a pain control regimen so as to impact quality of life as little as possible. This should become standard practice as recommended in the North American clinical management guidelines for HS.[1] Access to pain medications can often be very challenging for patients, due to heightened awareness of their addiction potential. It is important for family physicians to screen patients for pain, for patients to be able to quickly access pain specialists, and for HCPs to work together with patients to explore methods of pain management that are safe and effective, and be able to address the significant levels of pain that accompany HS.

V. SUPPORTING THE NEEDS OF PEOPLE LIVING WITH HS

10. Enhance availability and access to patient resources that provide information on treatment options and support groups for newly diagnosed patients. Those who have just received a diagnosis of HS often feel "shame", "scared and hopeless", "stressed", and "embarrassed". Being handed a resource that summarizes common triggers, the various lifestyle modifications, dietary changes, non-prescription and prescription drugs, and surgical procedures available, as well as links to supports, may provide much needed reassurance.

11. Continue to increase public awareness of HS. Much of the psychosocial impact of HS is due to the reactions of others (family members, intimate partners, employers) who are not familiar with HS, and under hurtful misconceptions: that it is caused by poor hygiene, that it is contagious, etc. Increasing general knowledge of HS would support the mental wellbeing of people with this condition while indirectly facilitating diagnosis.

*CADTH: Canadian Agency for Drugs and Technologies in Health
CSPA: Canadian Skin Patient Alliance
FED: Federal government
HA: Hospital administration
HCP: Healthcare providers
P/T: Provincial and Territorial governments
PRIV: Private payers
SG: Support groups