

Scarred for Life: 2020 Update

A NATIONAL REPORT
OF PATIENTS'
EXPERIENCES LIVING
WITH HIDRADENITIS SUPPURATIVA



May 2020

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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.

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.

"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."

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.

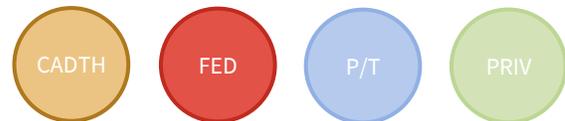


5. Expedite access to procedures. Those that are suffering from emergent symptoms involving discharge and excruciating pain should be able to access office-based procedures and surgical interventions (including those requiring operating room time) in a timely manner.



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

BACKGROUND

Hidradenitis suppurativa (HS) is a chronic inflammatory dermatological disease affecting from 1% to 4% of the general population.^{2,3} Its symptoms are physically and emotionally debilitating, and include painful boils and abscesses in the folds of the skin, primarily in the armpits, groin, between buttocks and under the breasts.^{2,3} During a symptom flare, the lesions are prone to purulent discharge and unpleasant smell, and may result in scarring and fistulas. Given the nature of these symptoms, the devastating impacts of HS are far-reaching in the lives of those afflicted, extending to their ability to work, socialize and conduct daily activities.⁴⁻⁶

In Canada, the prevalence of HS has been estimated at 3.8%.⁷ This condition affects females more commonly than males, at a ratio of 3:1, with average age of symptom onset in their 20s.⁸ Previous research found that the average Canadian patient with HS will see five physicians with 17 visits spanning eight years before being diagnosed.⁹ Once diagnosed, the difficult journey continues; since there is no cure for HS, patients often attempt numerous home treatments, rely on over-the-counter and prescription medications as well as surgical procedures to manage devastating symptoms. This trial and error process is fraught with little to no symptom relief and painful side effects, including scarring. A recent survey of 303 individuals with HS from Canada and the US found that nearly half did not experience marked improvements with conventional therapies.¹⁰ Additionally, more than 80% reported use of complementary and alternative medicine (CAM), including marijuana, magnesium sulfate baths, and topical cannabidiol oil – a much higher percentage than has been reported for many other chronic dermatologic diseases.¹⁰ However, less than 70% reported disclosing use of CAM to their healthcare providers, leaving them vulnerable to potential interactions with medications.

A 2015 study of 55 Canadian patients demonstrated that in addition to the detrimental impact on physical well-being, HS also has severe psychosocial effects, based on patient-reported outcomes.¹¹ A separate Canadian study of 51 individuals with HS found that those with severe foul-smelling discharge from their lesions had severe quality of life impairment.¹² It is therefore unsurprising that a large review of data from over 40,000 individuals with HS, including those from Canada, showed that 17% of people living with HS experienced depression and 5% of them experienced anxiety, which are significantly higher than the rates found in the general public.¹³ A separate systematic review of the HS literature found even greater prevalence of depression (21%) and anxiety (12%) in this population.¹⁴

In 2017, the Canadian Skin Patient Alliance (CSPA) – a not-for-profit organization founded to support those living in Canada with skin disorders – identified the need to comprehensively describe the experiences of individuals with HS and support the development of tools and support services to address existing gaps in their care, and inform healthcare decision-making. The survey's findings provided a baseline measure for HS care in Canada, and

identified various gaps in patient care resulting in misdiagnoses, painful symptoms that cannot be managed by available treatments, and further stress and psychological impact to those afflicted, with effects extending throughout all aspects of their lives (**Appendix**).

In 2020, we asked people living with HS to tell us more about their experiences, and compared our findings to those obtained three years earlier. We invited individuals with HS in Canada and elsewhere to participate. In this report, we have described our survey's results, and the progress of Canada's healthcare system towards improving care for patients with HS. This report also presents much-needed data on universal HS patient experiences.

METHODS

The CSPA developed the online Hidradenitis Suppurativa Patient Experience (HSPE) survey in collaboration with the Canadian HS Foundation and HS Aware in 2017. For the 2020 iteration, our survey team updated the survey with additional questions on the impact of HS. The goal was to more comprehensively examine how all aspects of daily lives are affected.

We invited all individuals with a formal diagnosis of HS, or a self-diagnosis based on the presence of HS symptoms, to complete the survey. Unlike the 2017 survey, we extended the eligibility criteria to include individuals living outside Canada and the United States, since many patient experiences regarding the impact of this condition are likely to be irrespective of geographical location.

The survey was created in [Survey Monkey](#) and designed to be completed within 25 minutes.

HSPE survey dissemination

We disseminated the HSPE Survey link through a number of methods to access individuals with HS both within Canada and elsewhere:

- CSPA's website and social media channels
- Canadian HS Foundation
- Patient Commando's social media channels
- Local, national and international HS patient groups

The survey was open from January 6 to February 17, 2020.

We supplemented the survey results with data from the Canadian Institute for Health Information (CIHI) on HS-related ER visits and hospitalizations from 2017 to 2018. Data from 2010 to 2016 were obtained for our 2017 report and are included here as well.

RESULTS

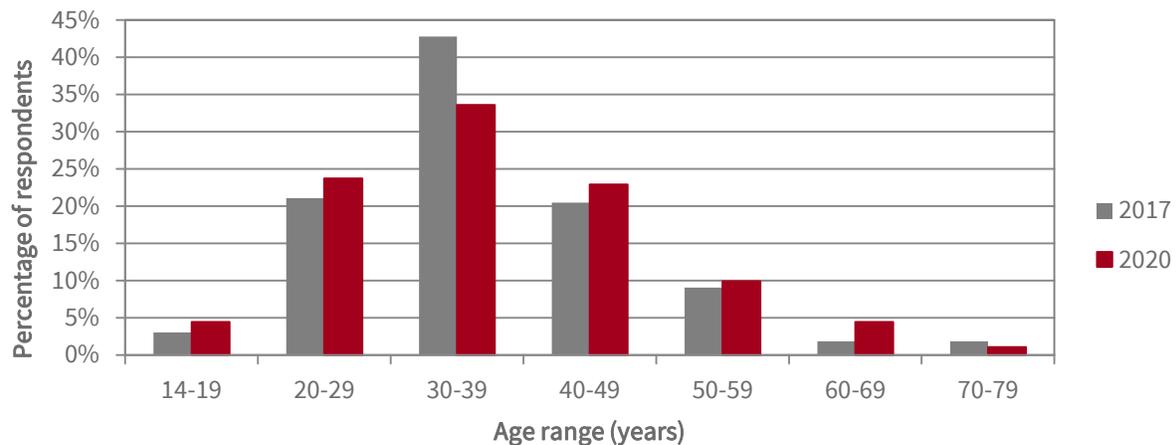
A total of 537 surveys were received from eligible respondents, significantly more than the 167 individuals who responded to the 2017 survey. This is likely due to the expansion of our recruitment outreach combined with opening eligibility to include those outside of Canada and United States. Of the total, 515 (96%) were from individuals who had been formally diagnosed with HS by a healthcare provider (HCP) while the remaining 22 (4%) were from those self-diagnosed only. It took individuals an average of 21 minutes to complete the survey.

i. DEMOGRAPHICS

The majority of survey respondents were biologically female (93%), and the average age was 38 years with a range of 14 to 73 years. Most (85%) were under the age of 50 years (**Figure 1**). Of the 390 individuals that reported their gender identity, 91% identified as female, 7% as male, 1% as gender-queer, and 1% indicated a different but unspecified identity.

Although we expected a higher response rate from biological males based on previous research indicating that 25% of individuals with HS are male, the survey's demographics are likely to be reflective of a higher female presence in online support groups, our key method of recruitment. This was also the case with the 2017 survey, for which 4% of respondents were male.

Figure 1: Age of Survey Respondents (n = 384)



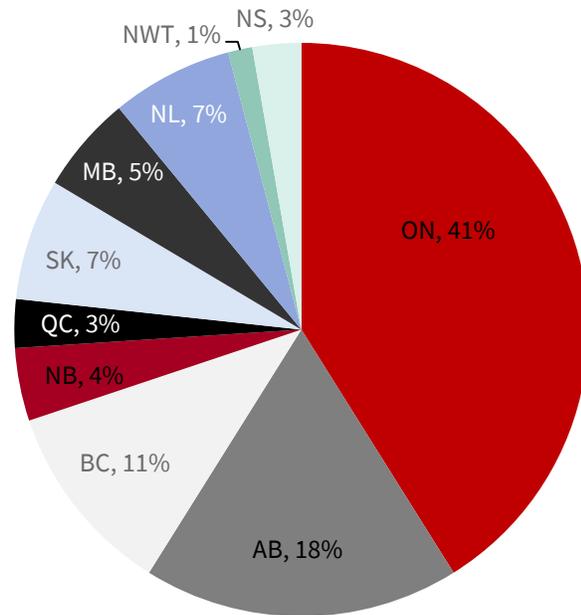
Of all respondents, 73 were from Canada (14%, **Table 1**), 267 from the United States (50%), 67 from the United Kingdom (12%), and the remainder from several other countries across the world. The highest proportion of Canadian responses came from Ontario (**Figure 2**). In 2017, 54% of the 50 Canadian surveys were from Ontario. This is less likely due to higher HS prevalence in this province but rather because it has the largest population, and therefore more cases of HS than other provinces and territories.

**Table 1:
Respondents' Geographical Location***

Country	# of Surveys
Australia	8
Canada	73
India	8
Ireland	23
Netherlands	45
Sweden	27
United Kingdom	63
United States	267
Albania, Belgium, Denmark, Greece, Iceland, Malaysia, Montenegro, Morocco, New Zealand, Nigeria, North Macedonia, Puerto Rico, Singapore, Slovenia, South Africa, UAE*	23
Total	537

*1-3 surveys from each country

**Figure 2:
Provincial Distribution of Surveys, by Percentage**



We have divided the survey results into sections, presenting data from respondents living in Canada for sections regarding diagnosis, cost and healthcare utilization, and from all respondents for the remaining sections, as outlined below.

Respondents from Canada	All respondents
I: Seeking a Diagnosis in Canada	III: Effectiveness and Use of Treatments to Prevent and Control HS
II: Diagnosis and Management of HS	VI: Pain Management
IV: Cost of Treatments to Prevent and Control HS	VII: Impact of HS of Daily Life
V: Healthcare Utilization	VIII: Knowledge of HS
	IX: HS-Related Patient Needs

Section I: Seeking a Diagnosis in Canada

i. HEALTHCARE UTILIZATION

We asked about the number of *different* HCPs seen by patients in Canada during the period from symptom onset to HS diagnosis (**Figure 3**).

- Ninety-seven percent of the 67 respondents visited a family physician or walk-in clinic doctor regarding symptoms, and 61% saw 3 or more. In our 2017 survey, 90% of respondents saw a family physician for symptoms but we did not ask specifically about walk-in clinic visits at that time (**Figure 4**)
- More than half of all respondents (59%) visited the ER for HS symptoms (up from 50% in 2017); 11% visited the ER more than 10 times, and were treated by more than 10 different ER physicians (a decrease from 18% in 2017)
- The majority (75%) visited at least 1 dermatologist (a slight increase from 70% in 2017), and 17% saw more than 3
- Only 28% were referred to a surgeon during their ER visit for HS symptoms (slightly more than 23% in 2017), while 42% consulted with a surgeon based on a referral from their family physician (a decrease from 47% in 2017)
- Gynecologists were seen during the pre-diagnosis stage by 17% of respondents, which is less than the 36% reported in 2017

Other specialists, primarily infectious disease (ID) specialists and endocrinologists, were seen by 20% of respondents in 2017. Our current survey shows that, similarly, 18% saw at least one ID specialist while 19% saw at least one other specialist or HCP (endocrinologist, wound care nurse).

Figure 3: Number of Different HCPs Consulted for Symptoms of HS Prior to Diagnosis (n = 67)

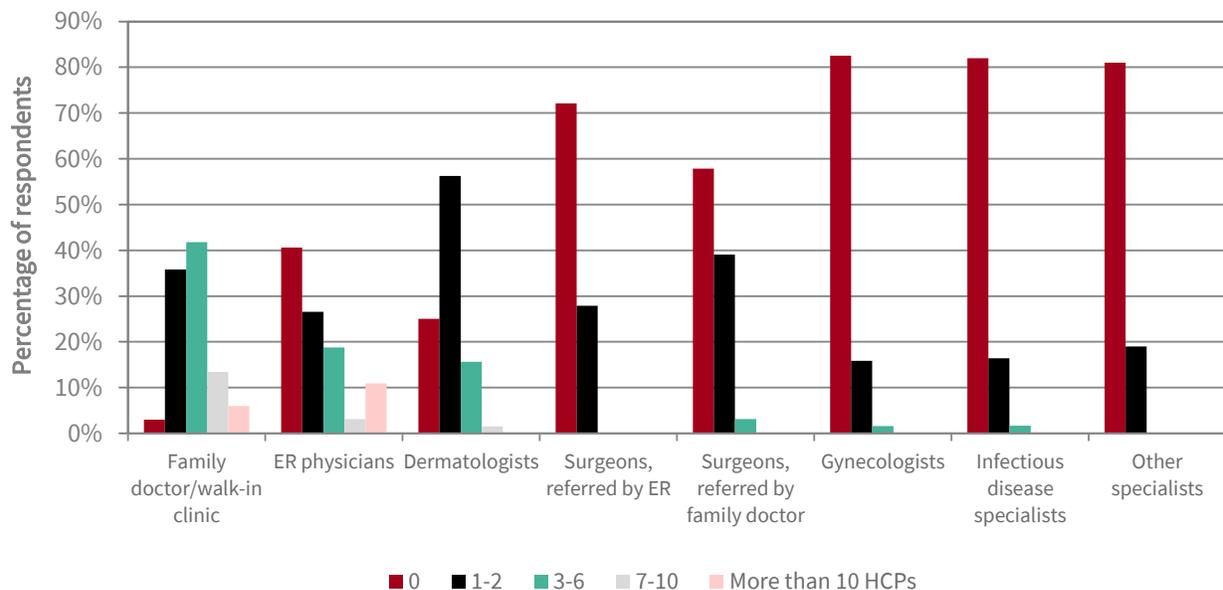
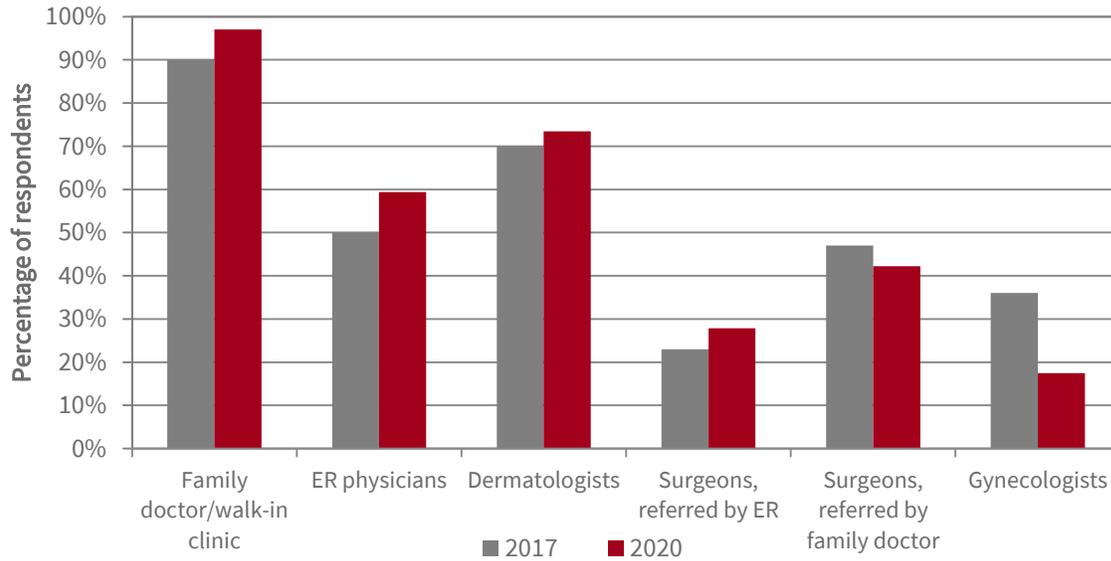


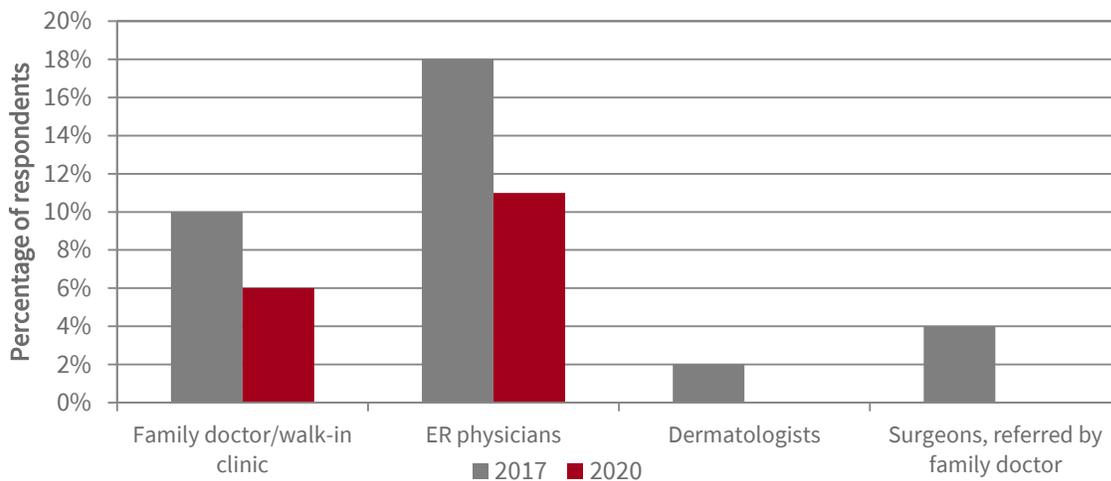
Figure 4: Comparison of percentage of respondents that consulted with at least one or more different HCPs for HS symptoms prior to diagnosis, in 2017 vs. 2020*



*2017 data did not include walk-in clinic visits

A smaller percentage of respondents visited more than 10 different family physicians, ER physicians, dermatologists, and surgeons referred by family doctors in 2020 than in 2017 (Figure 5). This may be indicative of quicker diagnosis journeys in recent years.

Figure 5. Comparison of percentage of respondents that consulted with more than 10 different HCPs for HS symptoms prior to diagnosis, in 2017 vs. 2020*

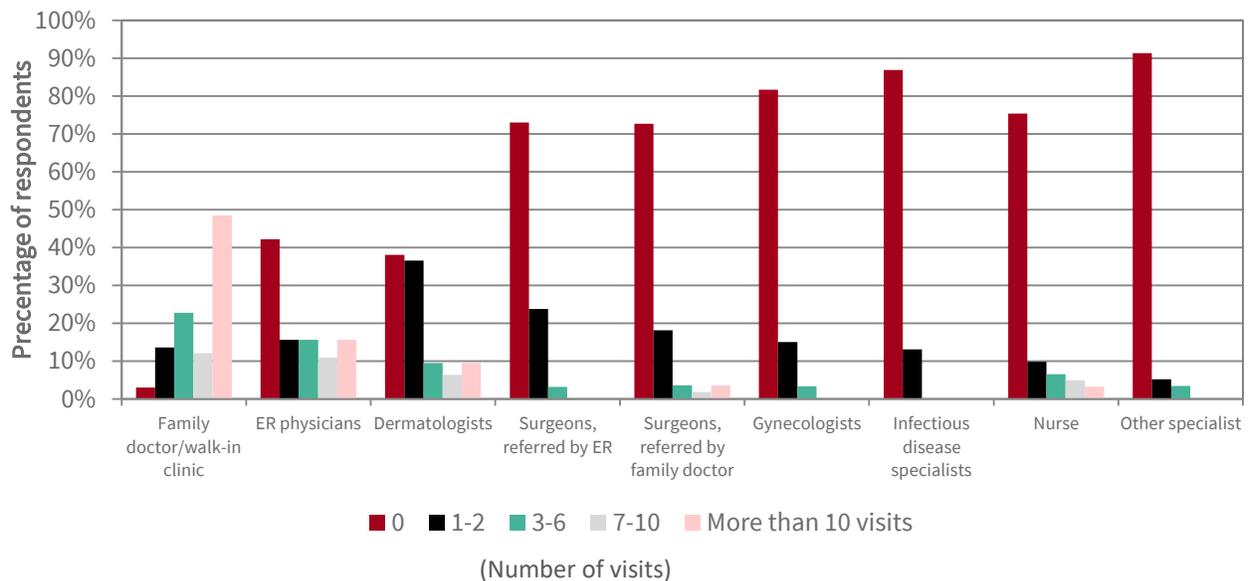


*2017 data did not include walk-in clinic visits

During the pre-diagnosis stage, respondents sought medical care repeatedly for symptoms of HS (Figure 6).

- Family physicians were seen frequently, with 48% making 10 or more visits (a slight decrease from 53% in 2017)
- 58% made at least one trip to the ER (increased from 49% in 2017); 16% visited 10 or more times (down from 30% in 2017)
- 62% visited a dermatologist at least once (72% in 2017) and 10% made at least 10 visits (17% in 2017)
- 27% visited a surgeon referred by the ER, and the same number visited a surgeon following referral by their family physician
- 9% of patients had medical visits with other specialists (e.g., endocrinologists, internists, oncologists)

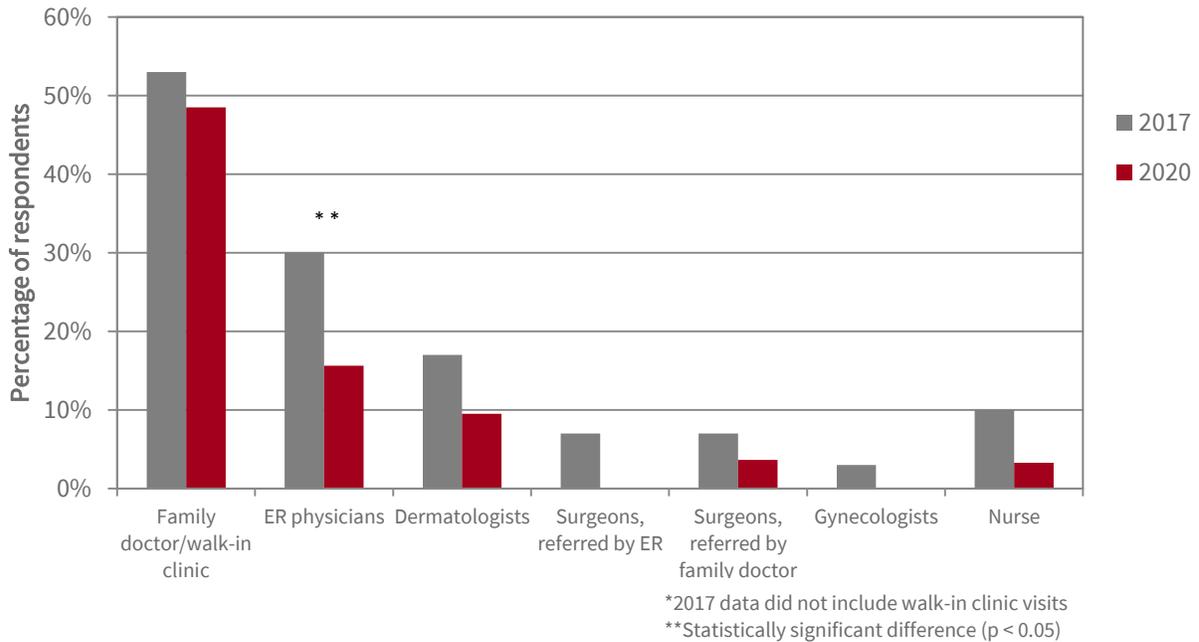
Figure 6: Number of Different Medical Visits for Symptoms of HS Prior to Diagnosis (n = 67)



“A general doctor doesn’t have knowledge about HS. They don’t know anything about the disease. They just give antibiotics. We need so much more... we need good treatment from day 1. Not 8 years later.”

There were lower percentages of respondents consulting with the same HCPs 10 or more times for HS symptoms pre-diagnosis based on the 2020 survey, compared to 2017 (Figure 7). While it is not possible to determine whether this is a trend, it is encouraging that individuals with HS may be receiving accurate diagnoses more rapidly than in the past.

Figure 7. Comparison of percentage of respondents that consulted with their HCPs 10 or more times for HS symptoms prior to diagnosis, in 2017 vs 2020*



ii. **WAIT TIMES**

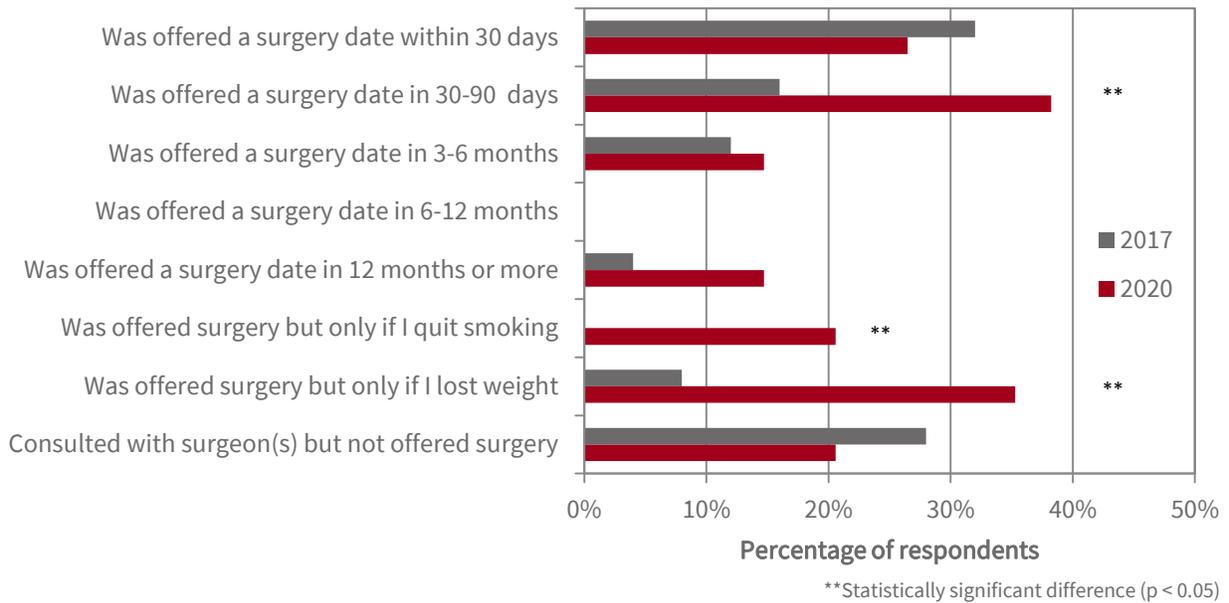
Prior to receiving a diagnosis, many patients from Canada were referred to dermatologists and surgeons, and often had lengthy waits for a consultation. The median waiting duration to see a dermatologist was 167 days (range of 0 to 1,820 days; n = 61 patients), which was an improvement over the 180 days reported by respondents in 2017.

Twenty-two individuals (36%) reported that they had not consulted with a surgeon. Of the 34 who provided information on referral time to see a surgeon for HS symptoms, the median wait time was 180 days (significantly higher than the 150 days reported in 2017).

Thirty-five percent of the 34 respondents were informed they needed to lose weight first (Figure 8), and 21% that they had to quit smoking first (we did not specifically ask about these conditions in 2017, though 8% of respondents indicated that their surgeon required that they first lost weight). A lower percentage of respondents were offered surgery within 30 days in the recent survey compared to earlier (26% in 2020 and 32% in 2017).

“I diagnosed myself and it still took another 5 years to get a professional diagnosis. The hardest part is knowing it’s incurable and that my children could develop it.”

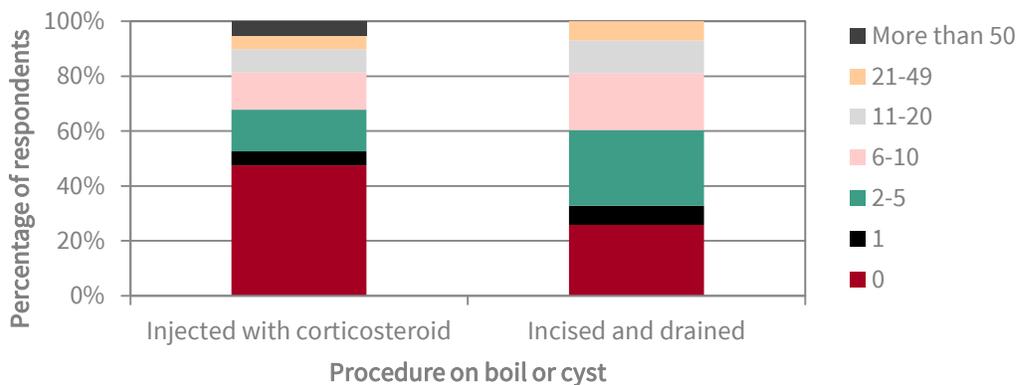
Figure 8: Surgery Wait Times (n = 34)



iii. PROCEDURES ON BOILS AND CYSTS

Fifty-three percent of respondents from Canada had at least 1 injection with Kenalog (a corticosteroid), while 18% had this performed more than 10 times (Figure 9). Additionally, 74% had at least 1 boil or cyst incised or drained, and 19% went through this procedure more than 10 times.

Figure 9: Number of Procedures on Boils/Cysts (n = 58)



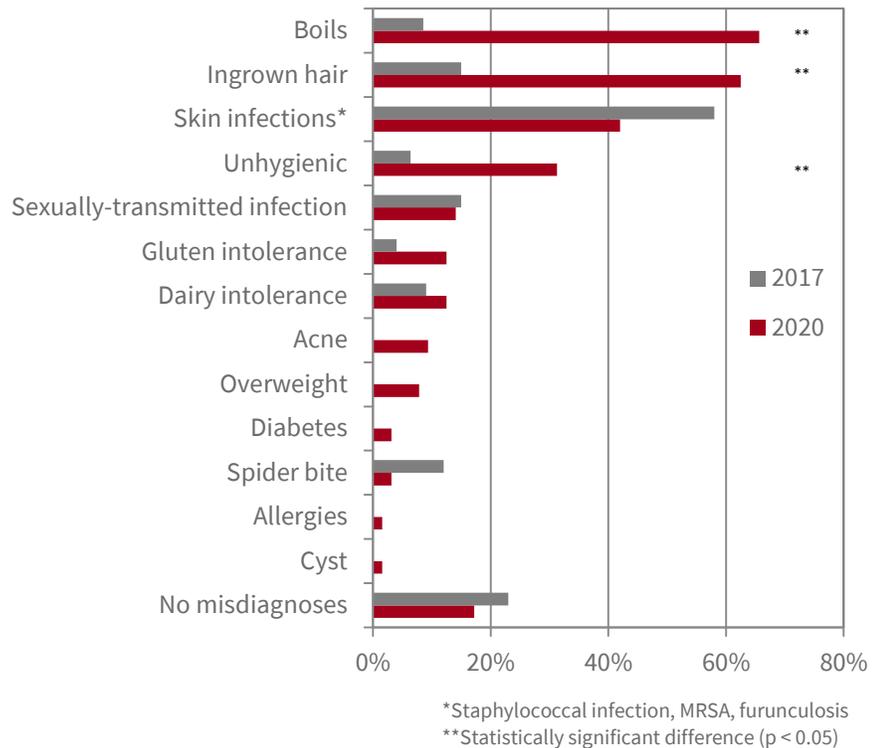
iv. MISDIAGNOSES

Prior to receiving a diagnosis of HS, 83% of respondents from Canada received at least 1 misdiagnosis, similar to the 2017 result (78%). The average rate was 3 misdiagnoses per person (range was 0 to 10).

“It was hell trying to figure out what was wrong and it’s hell trying to treat it. Being misdiagnosed so many times and put on so many medications that didn’t work but brought their own symptoms was torture in and of itself.”

There are considerable differences between 2017 and 2020 in the types of misdiagnoses being given to individuals with HS. Our current survey’s results indicate that the most common misdiagnosis was boils, reported by 66% of respondents (**Figure 10**), and ingrown hair (63%). In 2017, we did not specifically ask about boils; the most prevalent misdiagnosis was “skin infection”, reported by 59% of survey respondents. STIs and ingrown hair were the next most prevalent misdiagnoses, with each reported by 15% of respondents.

Figure 10: Percentage of Respondents with Misdiagnoses (n = 64)

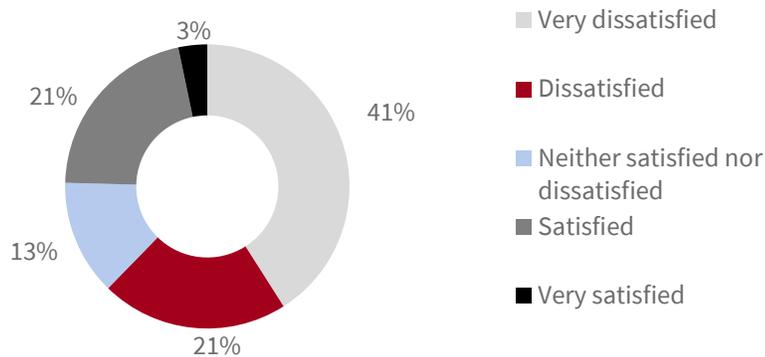


v. SATISFACTION WITH THE HEALTHCARE SYSTEM

Given the length of time from symptom onset to diagnosis, coupled with the frequent misdiagnoses, it is unsurprising that the majority of respondents from Canada were dissatisfied (21%) or very dissatisfied (41%) with their healthcare system during this period (**Figure 11**). This is a slight improvement over the 2017 results, when 16% reported dissatisfaction and 53% strong dissatisfaction with their pre-diagnosis experience.

When asked to explain the reason for their rating, those who were dissatisfied expressed that their interactions with their healthcare providers when seeking a diagnosis were very frustrating. They did not feel believed, respected, or listened to, and were frequently dismissed, often with prescriptions for antibiotics or instructions to lose weight or improve their hygiene.

Figure 11: Satisfaction with Healthcare System while Seeking Diagnosis (n = 61)



They did not feel that physicians had an awareness of HS, which caused them to go undiagnosed and for their disease to continue to progress with only band-aid solutions, as they attempted to find other HCPs who could offer a true diagnosis. Several respondents felt forced to seek advice outside of their healthcare system, turning to online health groups where they were finally able to understand their symptoms.

“I was constantly being told it would go away if I lost weight. Told that I couldn’t be in pain. Was dismissed by walk-in clinic doctors in 3 different provinces, and never referred to a specialist. Was treated like it was my fault. It was a long frustrating process, and it caused me depression.”

Respondents who were neither satisfied nor dissatisfied with the experience commented that even though their HCP could not diagnose their symptoms, they were shown compassion, and referred to others who may have insight.

The respondents who indicated satisfaction during this period were typically those that were seen by HCPs who recognized the symptoms as HS fairly immediately. Many respondents also provided a “satisfied” rating if their HCP – while perhaps not familiar with HS themselves – took into consideration the information on HS that the patient provided them from their own online research, and acted quickly to make an official diagnosis.

vi. COMPARISON OF RESULTS FROM CANADA AND OTHER COUNTRIES

We compared key aspects of the pre-diagnosis journey reported by respondents from Canada and those living elsewhere.

Wait times to see dermatologists and surgeons

The median waiting duration to see a dermatologist was 167 days for respondents living in Canada. This was nearly three months longer than the 84 day median wait time reported by respondents from other countries.

For respondents from Canada, the median wait time to see a surgeon after a referral was made was 180 days, while respondents from elsewhere reported waiting a median wait time of 56 days.

Misdiagnoses

Respondents from Canada had similar experiences with misdiagnoses by HCPs, as those from elsewhere in the world. Both groups reported an average of 3 misdiagnoses while seeking a diagnosis for their symptoms of HS. Additionally, the three most common misdiagnoses given to respondents from Canada and other countries were *boils*, *ingrown hair* and *skin infections*.

Satisfaction with healthcare system pre-diagnosis

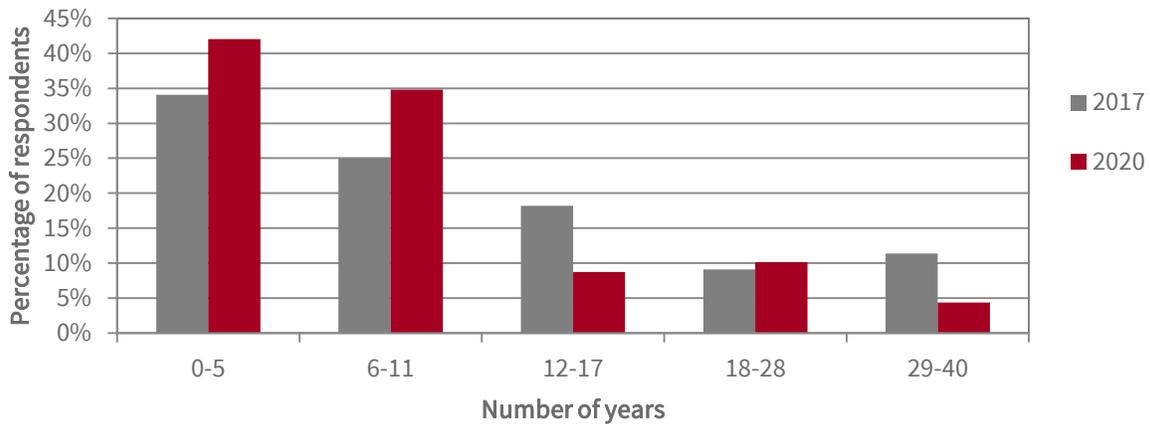
Despite notable differences in wait times shown above, the majority of all individuals were unhappy with their healthcare system experiences while seeking a diagnosis for their symptoms of HS, regardless of whether they were from Canada or another country. Of respondents from Canada, 62% were dissatisfied or very dissatisfied, while 64% of those from other countries reported being dissatisfied or very dissatisfied. Slightly more respondents from Canada were satisfied or very satisfied with their experiences compared to those from elsewhere (24% vs. 17%, respectively).

Section II: Diagnosis and Management of HS

i. DIAGNOSIS OF HS

Of the respondents from Canada, 69 reported on their length of time from symptom onset to HS diagnosis (Figure 12).

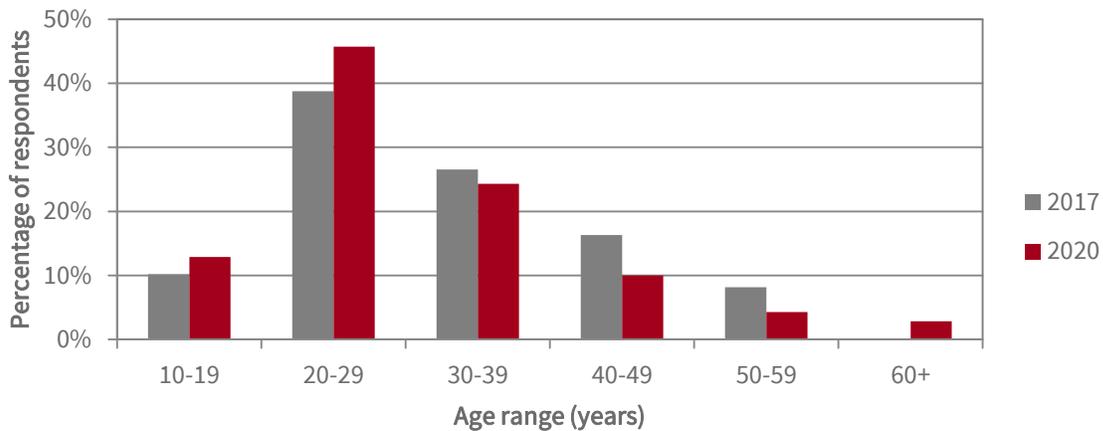
Figure 12: Number of Years from Symptom to HS Diagnosis (n = 69)



This ranged in duration from 2 months to 50 years, with a median time of 7 years, which is considerably quicker than the median of 9 years which was reported in the 2017 survey. The shorter time may be due to higher disease awareness among HCPs, patients seeking medical help for their symptoms more quickly, or could simply be the experiences of this sample (Figure 8).

The average age at diagnosis for the 70 respondents from Canada was 30 years (slightly younger than the 32 years observed with the 2017 data), with all respondents diagnosed between 13 and 71 years of age (Figure 13).

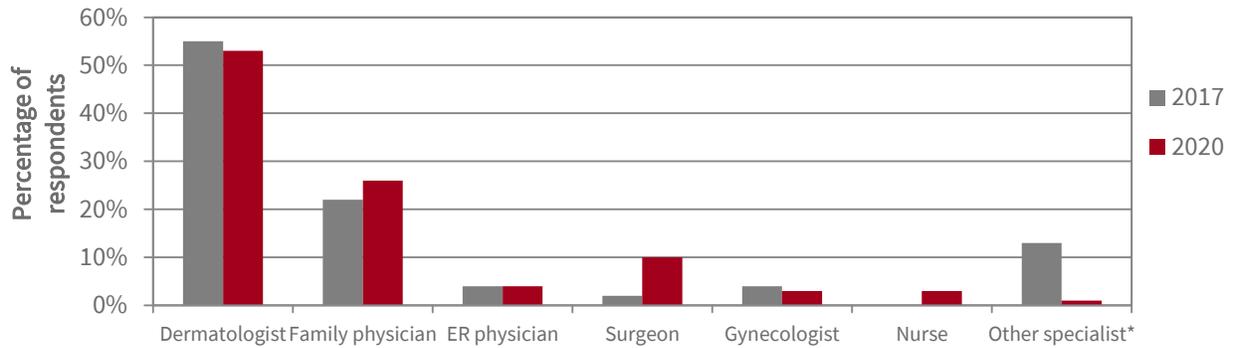
Figure 13: Age of HS Diagnosis (n = 70)



“It took 15 years of suffering to finally get told what it is. Then I got told there’s nothing you can do about it. You can only treat the symptoms.”

Similar to the results of the 2017 survey, the diagnosis of HS was most commonly made by a dermatologist (53%) and family physician (26%). Surgeons also diagnosed HS in 10% of the respondents, an increase from the 3% in 2017 (Figure 14).

Figure 14: Healthcare Provider Type Who Provided Diagnosis of HS (n = 70)



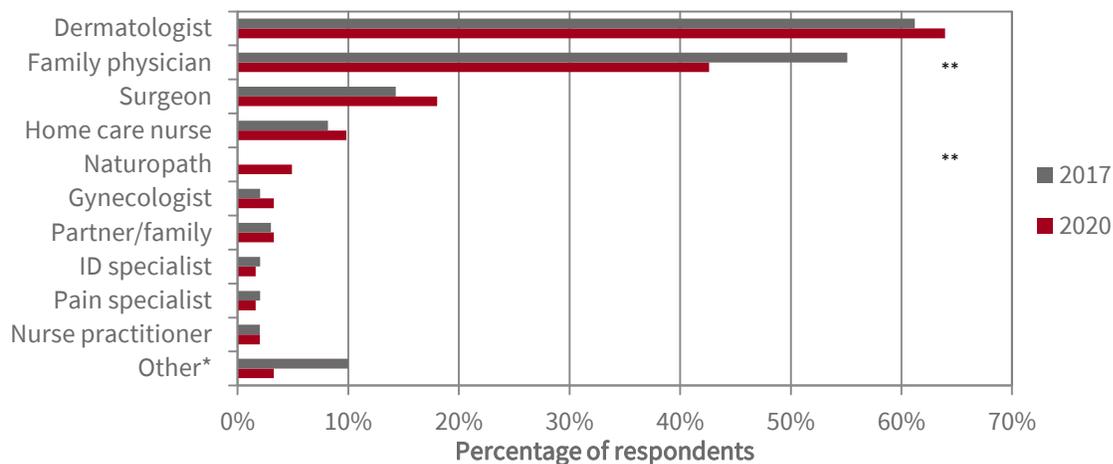
*Infectious disease physician, naturopath, walk-in clinic physician

“The first time I brought it up with my gynecologist, she sent me to a dermatologist who diagnosed it correctly immediately.”

ii. CURRENT HEALTHCARE TEAM FOR MANAGEMENT OF HS

When asked who helps them manage their symptoms of HS, 21% of respondents from Canada indicated that they do not have a healthcare team and are managing their symptoms on their own.

Figure 15: HCPs Included in Current Care Team for HS Symptoms (n = 61)



*ER physician, rheumatologist, internist, online support groups

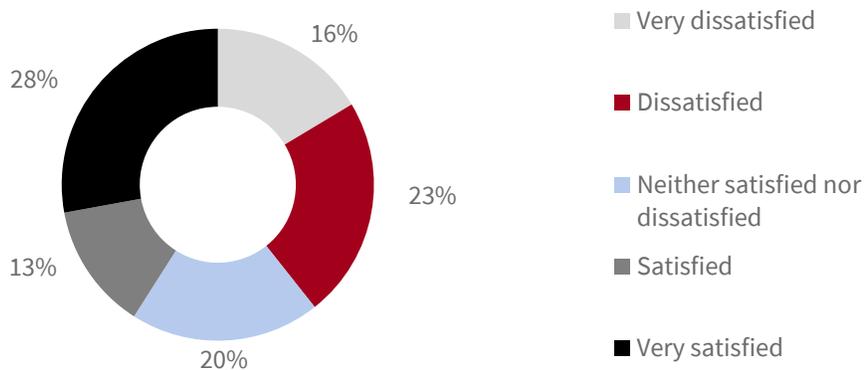
** Statistically significant difference (p<0.05)

The remaining respondents had at least 1 and up to 4 HCPs and family members in their circle of care for management of HS symptoms. There have been no major changes since the 2017 survey: dermatologists were most commonly reported as helping patients manage their condition, followed by family physicians and surgeons (Figure 15).

iii. SATISFACTION WITH CURRENT CARE FOR HS

Respondents indicated much higher satisfaction with their current level of care for HS, compared to when they were still seeking a proper diagnosis. Of 61 respondents from Canada who answered this question, 41% were satisfied or very satisfied with the healthcare system compared to 24% during the pre-diagnosis period (Figure 16). This is similar to the results we saw in 2017, when 43% of respondents indicated satisfaction with their then-current level of care for HS.

Figure 16: Current Satisfaction with Healthcare System for Treatment of HS (n = 61)



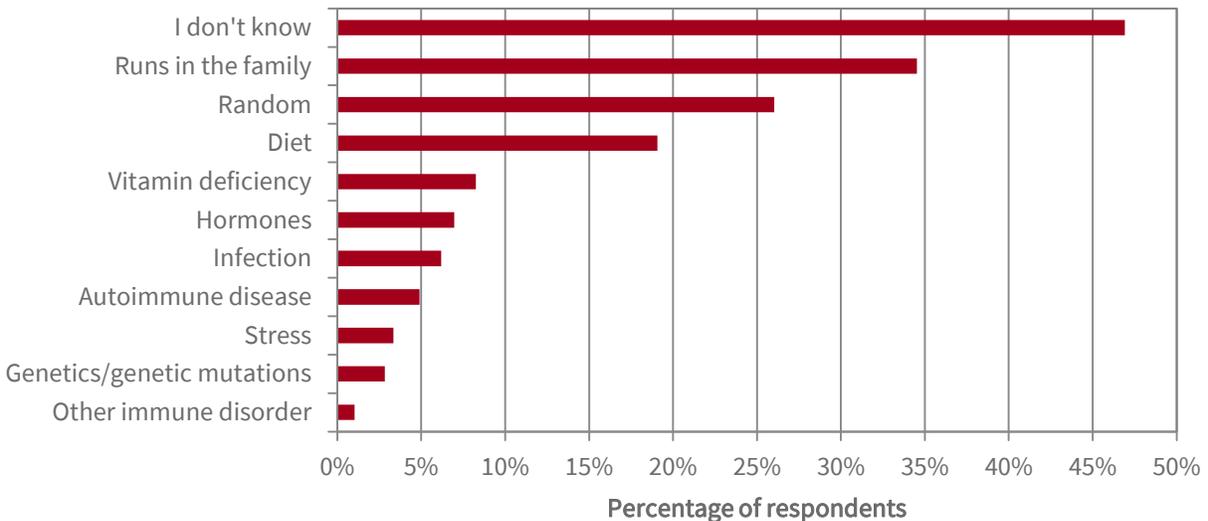
It was not possible to determine from the 2017 results the specific reasons for the improvement in satisfaction from pre- to post-diagnosis, and whether it was a result of better care, or simply relief to finally have a name for their condition. In our current survey, we asked respondents to explain their response, and the majority who indicated satisfaction reported that they did so because they had an HCP (typically a dermatologist) who was knowledgeable about HS. Interestingly only some stated that they had found a good treatment regimen – including diet changes, use of adalimumab, and surgical treatment – that was managing symptoms. Clearly, just having an understanding HCP who treated them with compassion, and was familiar with HS, elevated the respondents’ satisfaction with their healthcare experiences.

iv. CAUSE OF HS

Respondents were asked what they thought may be the cause(s) of HS (Figure 17), and of the

388 individuals from Canada and elsewhere who responded, the most common answers were “I don’t know” (47%), that it ran in the family (35%), and that it was a random condition with no true cause (26%).

Figure 17: Respondents’ Perceptions of HS Cause (n = 388)



v. COMPARISON OF RESULTS FROM CANADA AND OTHER COUNTRIES

We compared the data of respondents from Canada and those living elsewhere for several important measures related to the diagnosis of HS.

Time from first symptom to diagnosis

The median amount of time from first HS symptom to official diagnosis of HS was 7 years (range of 2 months to 50 years) for those in Canada, and 10 years and 2 months (range of 1 month to 52 years) for those outside of Canada.

Age at diagnosis

The average age at diagnosis for the 70 respondents from Canada was 30 years, with all respondents diagnosed between 13 and 71 years of age. Similarly, respondents outside of Canada were diagnosed at 29 years, on average (range of 8 to 63 years).

Current satisfaction with healthcare system

For respondents from Canada as well as those from other countries, satisfaction with their healthcare system increased considerably after diagnosis. Forty-percent of those from Canada and 41% of those from elsewhere reported being satisfied or very satisfied with their current care.

Section III: Effectiveness, Use and Satisfaction with Treatments to Prevent and Control HS Symptoms

i. EFFECTIVENESS AND USE OF TREATMENTS

Patients have tried multiple medications, surgeries and lifestyle modifications to prevent and treat HS symptoms (mean = 15; range of 1 to 27), reflecting both the severity of this condition and the desire to control the exacerbations and lessen the impact of symptoms (Figure 18).

Respondents used numerous at-home treatments, therapies and avoidance behaviours, and several reported that many of these were recommended by other patients with HS in online support groups and forums. The utilization of home remedies and lifestyle modifications is likely a result of them being more affordable and easier to access than some prescription medications and surgical treatments. Most respondents reported that, when they tried them, they offered either no or little improvement for HS symptoms, indicating the very individualized nature of this disease, and that what works for one person does not necessarily work for others.

Of all non-drug treatments described by respondents, stress management and diet modifications offered significant improvement to the most respondents, though still low, at less than 20% for each. Avoidance of tight-fitting clothing was also helpful with comfort and reducing exacerbation of lesions.

Antibiotics and over-the-counter (OTC) drugs were commonly used, though they offered very mild improvement or none at all. Of all treatments studied, the highest percentage of respondents reported that non-incision and drainage surgical treatment provided significant benefit at 23%. Biologics were used by 27% of respondents (26% in 2017); 10% of all respondents reported significant improvement in HS symptoms (8% in 2017). While long-course antibiotics were more commonly tried (82%; we did not ask specifically about these medications in our 2017 survey so are unable to compare to a baseline measure), only 9% of all respondents reported significant improvement.

Although only a small proportion of all respondents surveyed reported a significant improvement in their symptoms, for a few of the treatments and therapies this was a function of most having never used that specific option. When we examined the percentage who

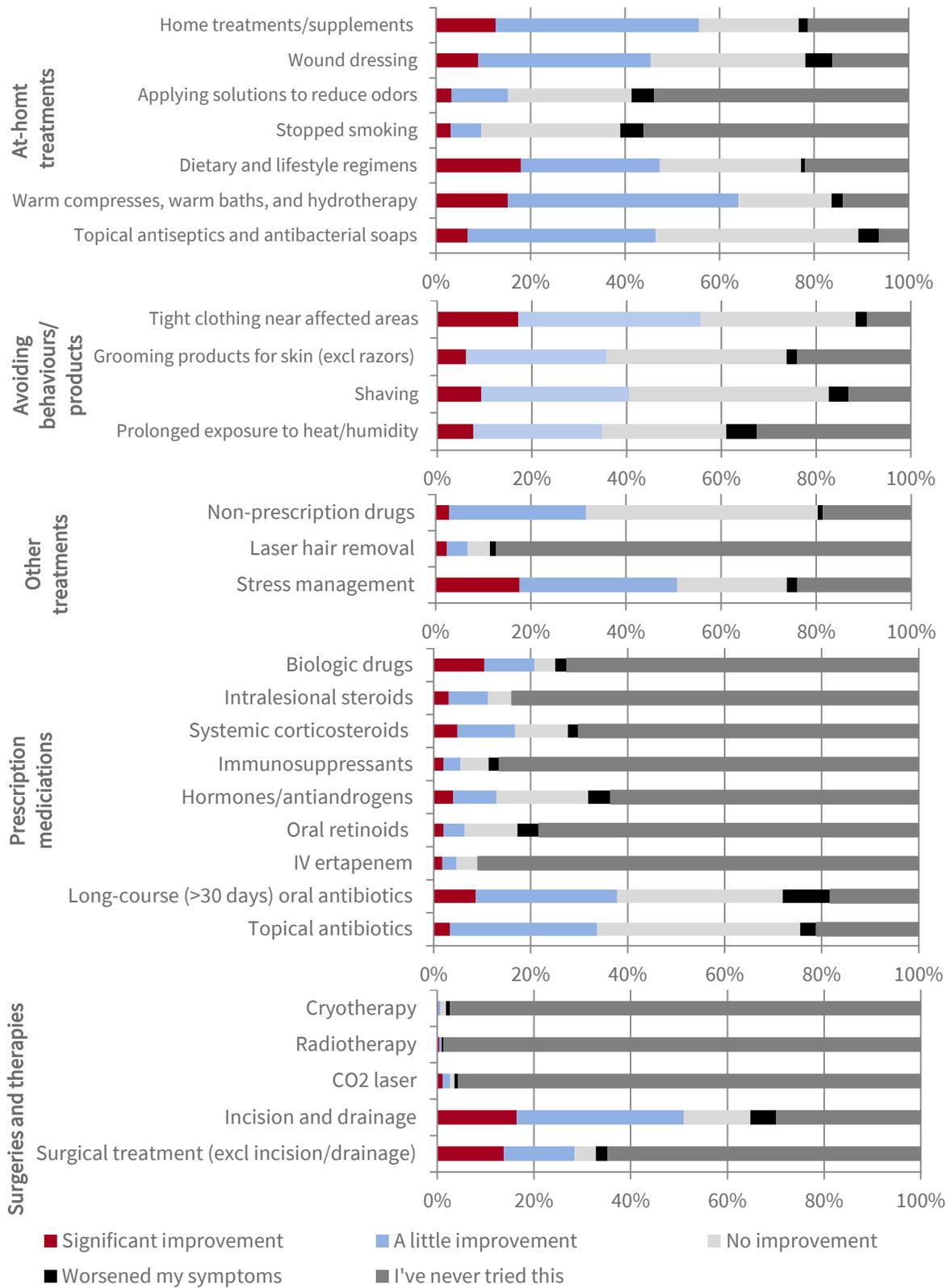
“This disease affects so many people yet the research is just in its infancy. I see so many new drugs come out for skin issues all the time but not for HS. It’s hard to stomach some times and is frustrating. We spend all of our time in pain and worrying about smells and bandages, and other skin diseases have multiple options covered by insurances to try.”

indicated significant improvement out of only those who had tried that particular treatment or therapy, we identified several that helped 25% or more users:

- CO₂ laser (a surgical tool): **26%** (5 out of 19)
- Radiotherapy: **33%** (2 out of 6)
- Biologics: **38%** (47 out of 124)
- Surgical treatment other than incision and drainage: **39%** (62 out of 159)

Although these treatments may be highly effective for a considerable proportion of individuals with HS, the fact that less than 35% of those surveyed had actually used any of them indicates that there are challenges with both timely access and affordability. We expand on respondent perceptions of the available treatments in the following sections.

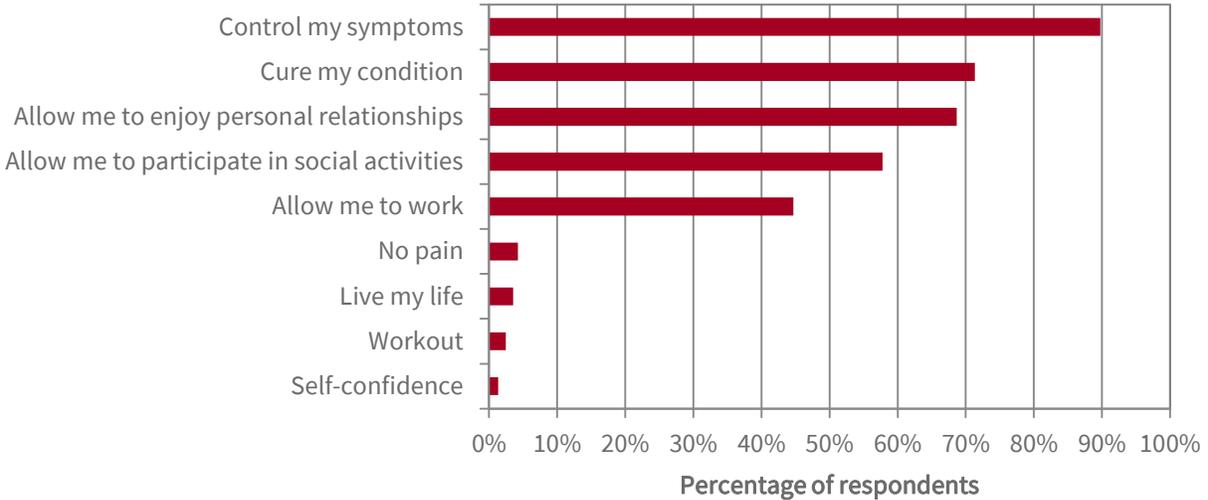
Figure 18: Effectiveness of Treatments to Prevent and Manage HS Symptoms (n = 462)



ii. TREATMENT GOALS

The primary goals for treatment were to control HS symptoms (90%), cure HS completely (71%), and be able to enjoy personal relationships (69%) (Figure 19).

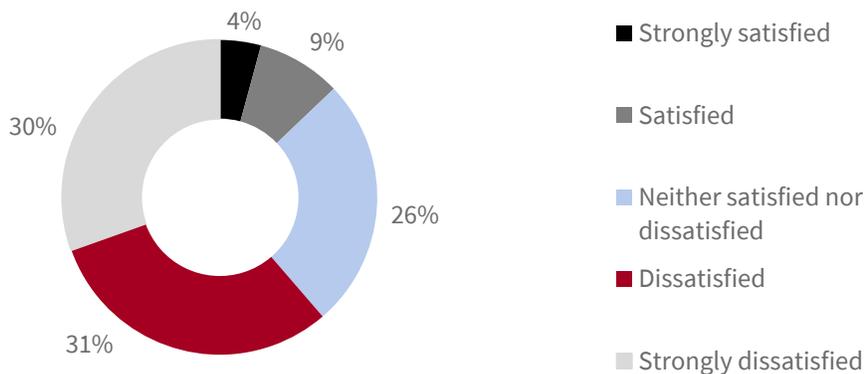
Figure 19: Respondents' Goals for Treatments for HS (n = 450)



iii. SATISFACTION WITH THE ABILITY OF HS TREATMENTS TO MEET GOALS

The majority of respondents (61%) were dissatisfied with the ability of currently available treatments and therapies for HS to meet the goals outlined in the previous section while an additional quarter of respondents were neither satisfied nor dissatisfied (Figure 20). It is evident that there is much room for improvement in terms of providing safe, effective and accessible treatments to individuals with HS, which allow them to control their symptoms and live their lives more fully.

Figure 20: Satisfaction with HS Treatments (n = 450)



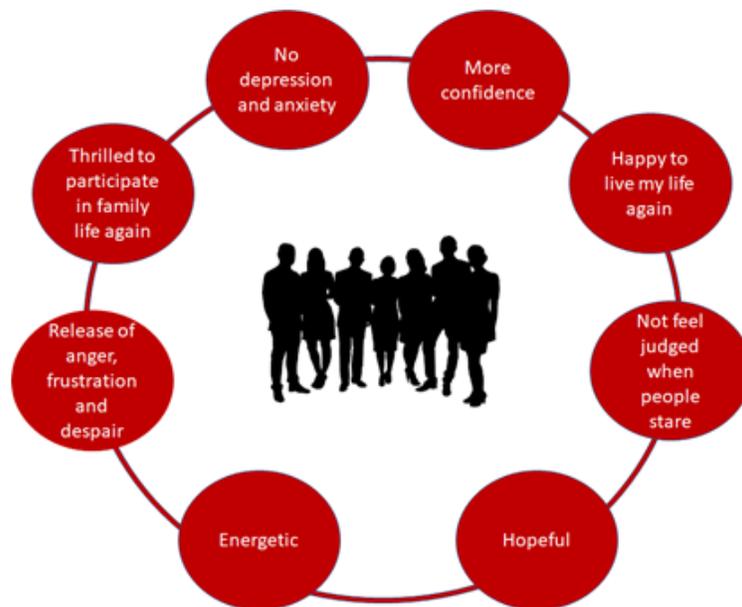
“Although we have come a long way from even 10 years ago to help manage HS, more needs to be done via research and making more biologics available (especially to us in Canada as adalimumab is the only one currently). Antibiotics are not the answer unless there is actual infection; we need to find why our bodies are doing this to us so we can tackle it and if not cure it, at least make HS way more manageable.”

The primary reasons for dissatisfaction were that treatments that were effective at significantly improving HS symptoms in the long-term often had side effects such as back pain, headache, intestinal problems and fatigue. Even surgery, which some respondents found quite helpful, had both a long wait time and an arduous recovery process in which it was impossible to work or properly care for family.

Access to promising treatments was often blocked by obstacles such as respondents’ HCPs not feeling it was worth trying until other options or lifestyle changes (particularly weight loss and smoking cessation) were exhausted. As a result, patients felt they were often forced to fight for access to new medications while being kept on problematic short-term medications such as antibiotics. Respondents also felt that effective options including new medications, were not covered and therefore not affordable.

iv. EXPECTED CHANGE IN EMOTIONAL WELL-BEING IF TREATMENT GOALS WERE MET

Survey respondents described a number of ways that they expected their emotional well-being to improve if they had a treatment that satisfied all of their unmet treatment needs. We have summarized these anticipated benefits below.



● ● ●

“It would be a miracle! This condition is so painful, so disgusting, and so life-altering. Talking with others, there is so much depression and pain associated with HS that it would be impossible not to show improvement with our well-being if all of our goals were met.”

● ● ●

While the vast majority of respondents indicated that a truly effective treatment would drastically improve emotional well-being, a small minority reported that their life would not be altered significantly or at all. For some, this was due to having fairly minor symptoms of HS. For others, past experiences with accessing medications led them to believe that even in the advent of a new, effective treatment, their physician would not prescribe it to them, or it would be unaffordable. Two patients reported that even if they were “cured”, the deep physical scars from years of suffering with HS would forever be a reminder of their illness, and negatively tinge their lives.

v. EXPECTED CHANGE IN DAILY LIFE IF TREATMENT GOALS WERE MET

Respondents reported numerous physical and emotional ways in which they anticipated their daily lives would change if they had a treatment that met all of their goals. We have organized these below, by theme.

Table 2: Anticipated Benefits of Fulfilled Treatment Goals for HS

Emotional benefits	Physical benefits	Benefits to daily life
<ul style="list-style-type: none"> • Less daily worry and anxiety • Could feel normal • Not worry about shame during sex • Not have to depend on others • Feel attractive • Happier at work and home 	<ul style="list-style-type: none"> • Be a better, more active parent to my children • Able to exercise, hike, and walk more • Wear any clothing without worry • Not worry about pain during sex • Full-range of motion 	<ul style="list-style-type: none"> • More time to manage other people’s problems and challenges instead of being so self-focused • Be less dependent on others • Able to work without asking for help from others • Able to have children • Have more time overall since no longer have to “prepare” self • Able to eat without worrying about triggering a flare

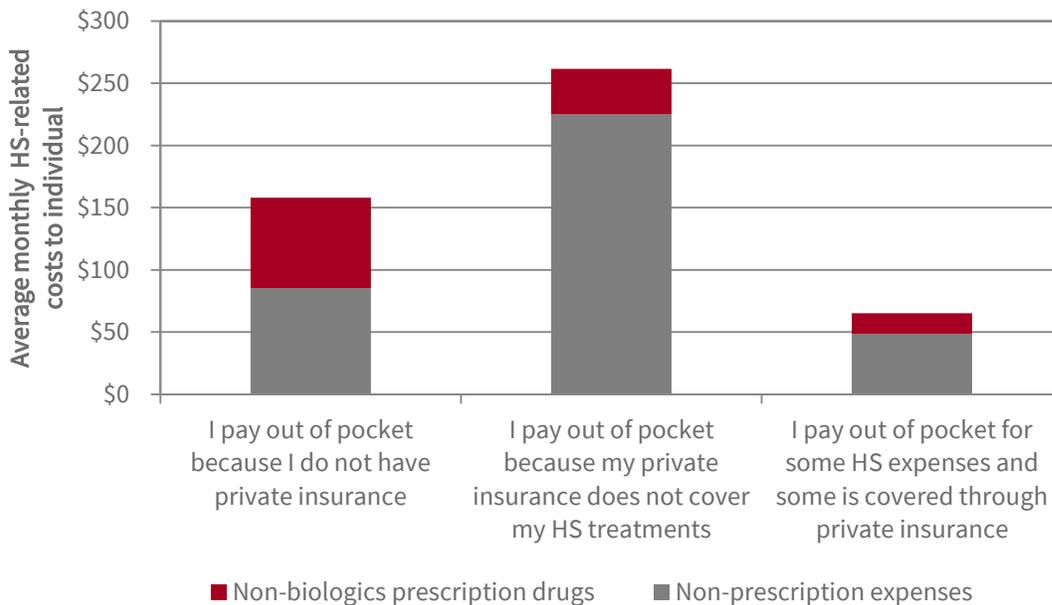
“To shower without grimacing and having to “psyche” myself up for it. To do less bandage changes. To not have to lay down all the time because I’m so exhausted or I’m in so much pain. To just be able to walk, to sit, to just be.”

Section IV: Cost of Treatments to Prevent and Control HS Symptoms

We asked respondents about their monthly HS-related expenses, and of the 55 individuals from Canada that responded:

- 6% were completely covered by private insurance so have no out-of-pocket expenses
- 22% did not have private insurance so pay entirely out-of-pocket
- 27% pay out-of-pocket because their private insurance does not cover any of their HS-related costs
- 45% have insurance coverage for some expenses and pay out-of-pocket for the remainder

Figure 21: Monthly Out-of-pocket HS-related Costs (n = 55)



For those who do not have insurance, HS-related monthly expenses were \$158, consisting of a roughly even split between prescription drugs (excluding biologics) and non-prescription items (this category included soaps, bath products, creams, wound care, non-prescription treatments/therapies, etc.) (Figure 21). Those who had private insurance that did not cover any HS treatments spent an average of \$262 every month (85% on non-prescription items and 15% on non-biologics prescription drugs). Those with private insurance that covered at least some HS-related expenses spent an average of \$65 monthly, with approximately \$48 on non-prescription items. Eight respondents indicated that they were on biologics (specifically, adalimumab, which is the only biologic indicated for HS in Canada) but did not pay because they were covered by the drug manufacturer's financial aid program. One respondent without any private insurance reported that they spend \$1,200 out-of-pocket every month on

biologics, while two respondents who have some private coverage reported that they pay \$17 to \$150 monthly for biologics.



“The cost of treatments is prohibitively high. I have insurance and can’t afford my copays, deductibles, and coinsurance. It comes down to seeing the doctor for an I&D or injections or taking into my own hands with a scalpel and buying food for my family at times and it shouldn’t.”



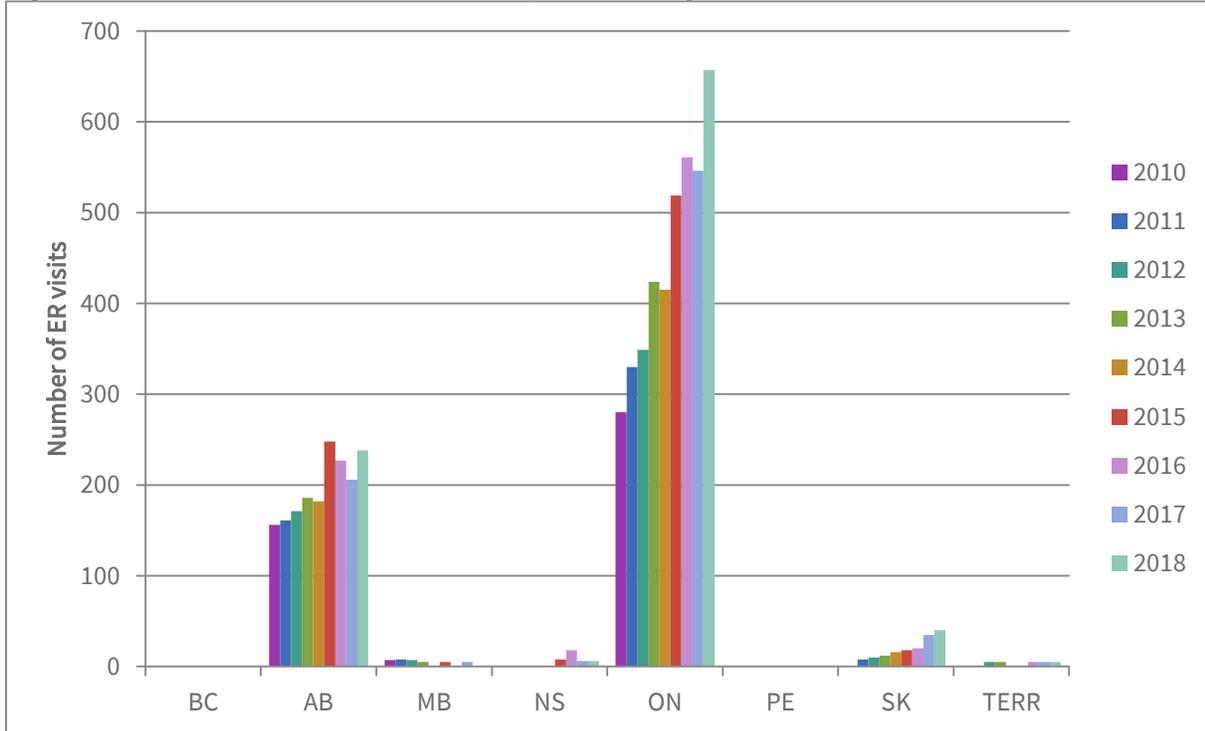
Section V: Healthcare Utilization – Data from the Canadian Institute for Health Information

We obtained provincial and territorial data on healthcare utilization – specifically, number of HS-related ER visits, and number of HS-related hospitalizations/lengths of stay – from the Canadian Institute for Health Information (CIHI). We combined this with data from 2010 to 2016 that we presented in our 2017 report. The data have some limitations: CIHI does not have access to provincial data from Quebec, and data from BC were only available for ER visits. Additionally, for privacy reasons, CIHI cannot provide specific data counts for 1 to 4 people.

Overall, the number of ER visits documented as HS-related continues to be fairly low across all provinces (**Figures 22 and 23**). Only partial data was reported for Manitoba, Nova Scotia, Prince Edward Island and the Territories. There are people visiting the ER in Manitoba, Nova Scotia and the Territories but no further trends are evident. Given that our survey results indicate that patients are commonly visiting the ER for HS symptoms when seeking a diagnosis, it appears that there may have been countless other visits leading to inaccurate diagnoses that were therefore not reported as HS-related.

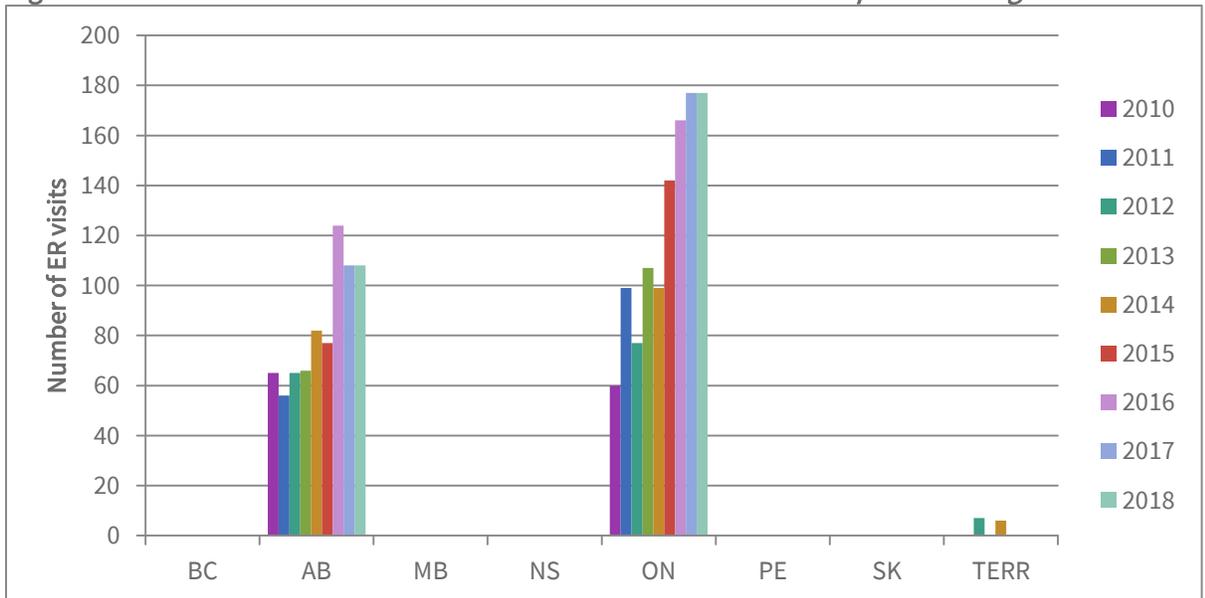
There were increasing number of visits in Alberta, Ontario and Saskatchewan between 2010 and 2018. The reasons are unclear; it may be the result of a growing overall population in these provinces (and therefore a growing population of individuals with HS). It may also be due to higher prevalence of HS over time, or changes in how the disease is coded and reported in medical charts. An increase in visits either due to HS or with HS as a concurrent condition may also be indicative of improved diagnosis. These same individuals may have always been visiting the ER for their symptoms but prior to diagnosis, they were not coded as having HS.

Figure 22: ER Visits for which HS is *Most Responsible Diagnosis*^{1,2}



¹Data were not reported for: BC (2010-2015), MB (2016), PEI (2017-2018); ²Counts of 1-4 were suppressed for privacy reasons: NS (2010-2014), PEI (2010, 2011, 2013, 2014), Territories (2010, 2011, 2014, 2015)

Figure 23: ER Visits for which Patient's HS is Noted but not as *Most Responsible Diagnosis*^{1,2}

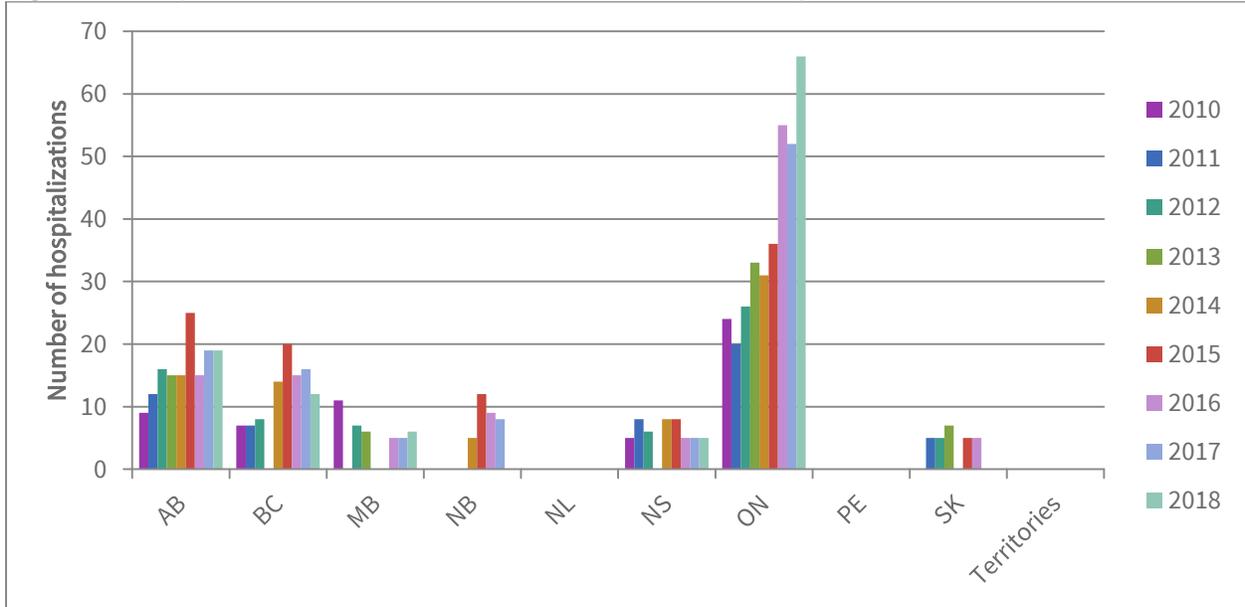


¹Data were not reported for: BC (2010-2015), MB (2017-2018), PEI (2017-2018), NS (2016-2018), SK (2016-2018), Territories (2016); ²Counts of 1-4 were not reported: MB (2010-2012, 2014) NS (2010, 2011, 2014); PEI (2011, 2012, 2015), Territories (2010, 2011, 2013)

Several provinces had HS-related hospitalizations, either with HS as a pre-admission comorbidity (i.e., the patient was diagnosed prior to being admitted to the hospital) or as

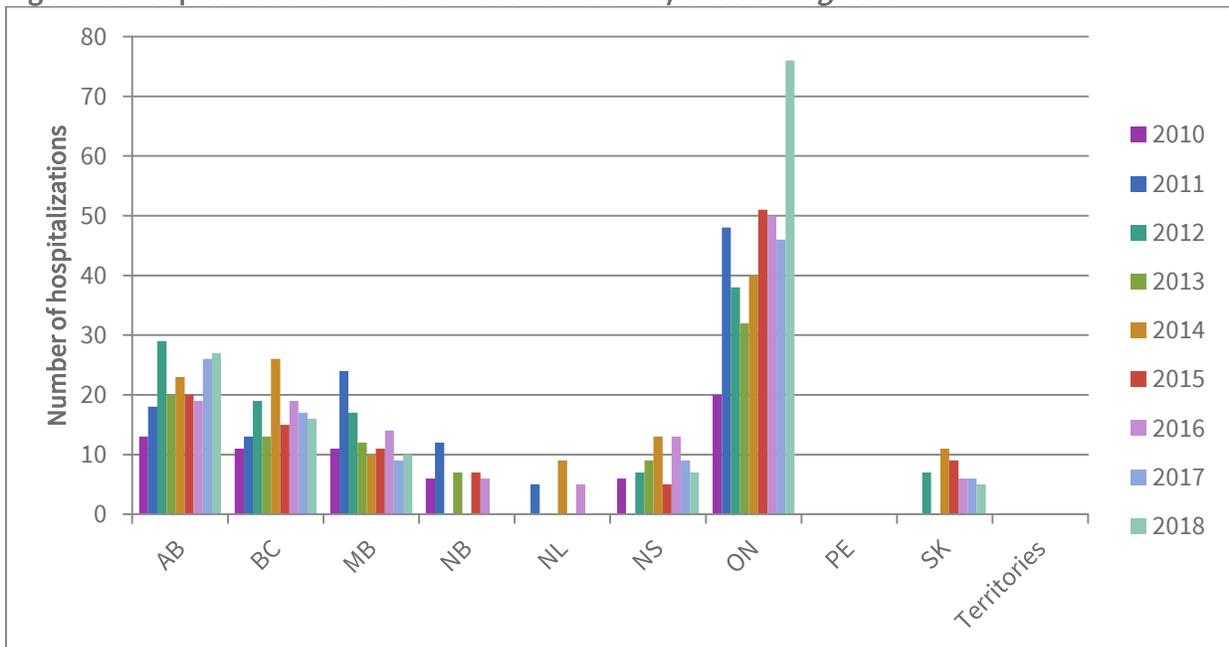
most responsible diagnosis (i.e., the main reason for being hospitalized) (Figures 24 and 25). Ontario in particular had substantially higher numbers than every other province and territory for every year within the study period, undoubtedly a result of its much larger population. The increase in HS-related hospitalizations in Ontario between 2010 and 2018 could again be due to population growth, increased HS prevalence, or better HS diagnosis.

Figure 24: Hospitalizations where HS was a *Pre-admit Comorbidity*^{1,2}



¹Data were not reported for: NB (2018), NL (2016-2018), PEI (2016-2017), SK (2017-2018); ²Counts of 1-4 were suppressed for privacy reasons: BC (2013), MB (2011/2014/2015), NB (2010-2013), NL (2010-2015), NS (2013), PEI (2010/2011), SK (2010/2014), Territories (2010/2013)

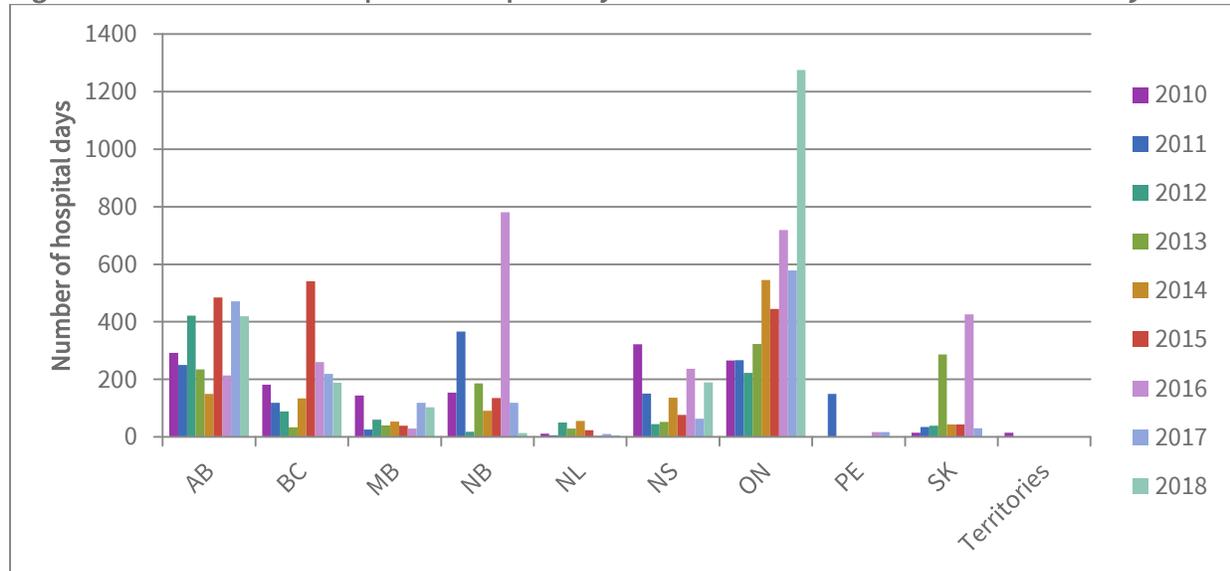
Figure 25: Hospitalizations where HS was the *Most Responsible Diagnosis*^{1,2}



¹Data not reported for: NB (2017-2018), NL (2017-2018), Territories (2016); ²Counts of 1-4 were suppressed for privacy reasons: NB (2014), NL (2010/2012/2013/2015), NS (2011), PEI (2014/2015), SK (2010/2011/2013), Territories (2013)

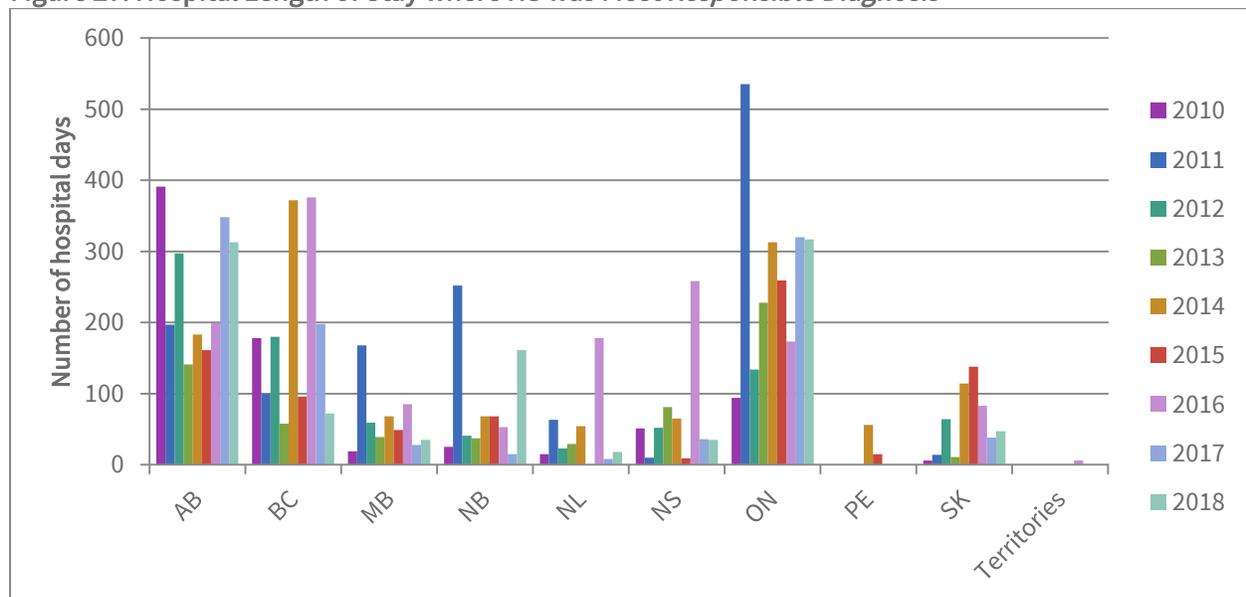
We also examined length of HS-related hospital stays (**Figures 26 and 27**), and observed large variation across provinces when HS was not the main cause for hospitalization (but was a pre-existing condition) and also when it was the most responsible diagnosis. For cases where HS was a pre-admission comorbidity, the length of hospital stay was dependent on the severity of the main indication but was potentially exacerbated by the presence of HS. Because there are so many possible symptoms associated with HS, it seems logical that the hospital length of stay would vary so considerably when HS is the most responsible diagnosis.

Figure 26: Total Number of Inpatient Hospital Days where HS was *Pre-admission Comorbidity*^{1,2}



¹Data were not reported for SK (2018); ²Counts of 1-4 were not reported: PEI (2010); Territories (2013)

Figure 27: Hospital Length of Stay where HS was *Most Responsible Diagnosis*¹

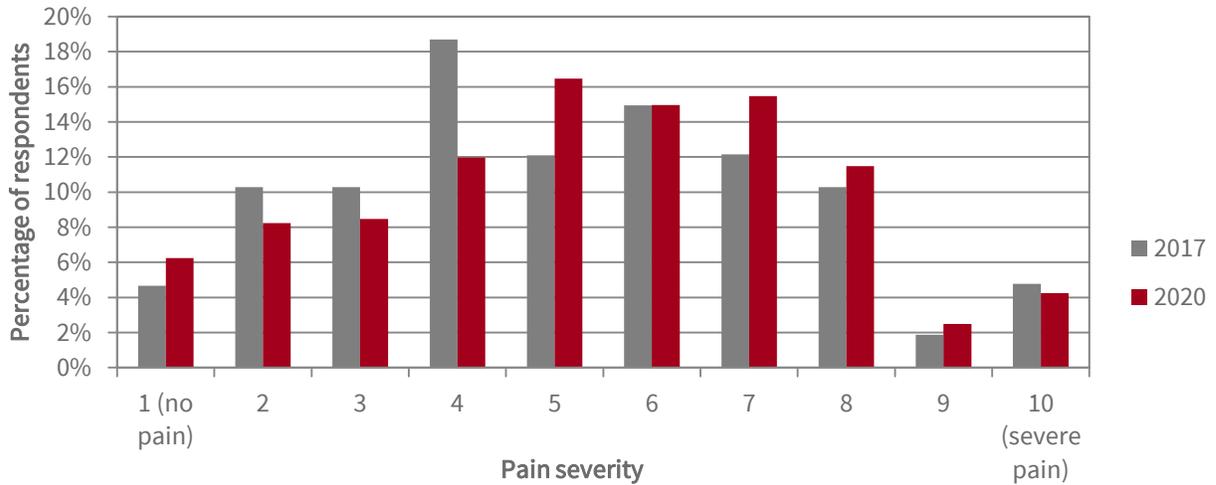


²Counts of 1-4 were not reported: NL (2015); Territories (2013)

Section VI: Pain Management

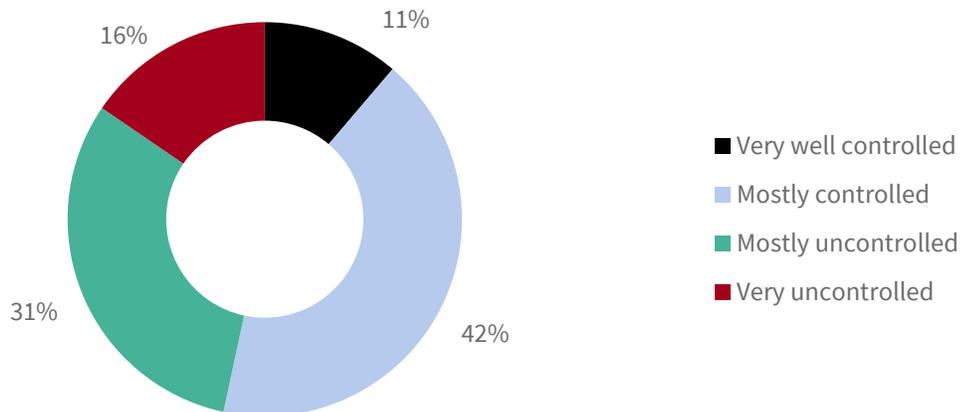
Pain is a debilitating symptom of HS, and can be acute or chronic in those with this condition. Respondents were asked to indicate their level of pain on a typical day from 1 (no pain) to 10 (severe pain, **Figure 28**). Nearly all patients experienced some degree of pain daily, and, on average, moderate pain (5.3 out of 10 vs. 5 out of 10 in 2017).

Figure 28: Pain Level on a Typical Day (n = 401)



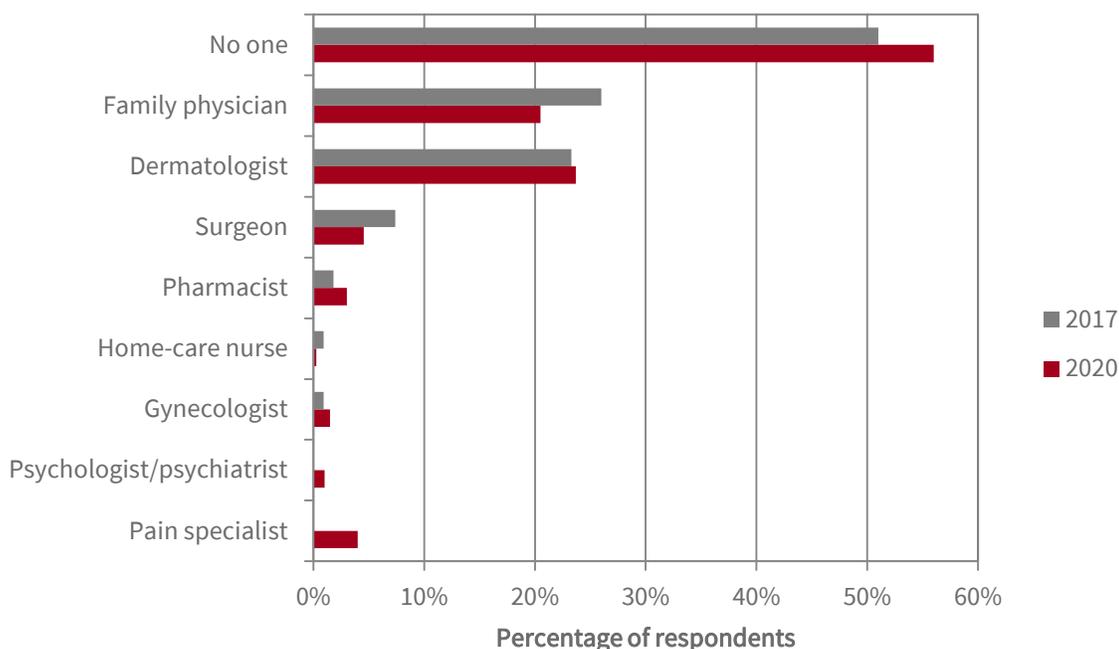
Most patients still do not have a successful pain management regimen. Only 11% of all respondents consider their pain to be very well-controlled, down from 19% in 2017 ($p < 0.05$; **Figure 29**). An additional 46% think their pain is poorly controlled, indicating that there is much room for improvement in helping patients manage this symptom.

Figure 29: Pain Control on a Typical Day (n = 401)



In 2017, 51% of respondents indicated that they manage their pain on their own without the help of an HCP (**Figure 30**). Based on the 2020 survey, that number had declined to 44%, with the remainder having their pain managed by at least one HCP (primarily, family physicians and/or dermatologists). Given the significant amount of pain that accompanies this condition, it is troubling that such a large proportion of patients are self-managing. Many patients commented on the difficulty of accessing prescriptions for effective pain medications from their HCPs, reporting that they were often made to feel that they were exaggerating this symptom and/or were only seeking medication to feed an addiction.

Figure 30: HCPs that Help Patients with Pain Management (n = 395)



Section VII: Impact of HS on Daily Life

i. TIME SPENT ON ACTIVITIES RELATED TO HS

Respondents spend a median of 14 hours (to a maximum of 234 hours) on tasks and activities related to HS every month (**Table 3**). Of all tasks, respondents reported that the most time-consuming was wound care, involving cleaning and bandaging their abscesses.

This is slightly less than what we observed in 2017 (15-20 hours), when survey respondents reported more time spent participating in online support groups, shopping for HS-related items and researching their condition.

These results do not include additional time off work, school or personal activities due to symptoms of HS.

Table 3: Time Spent on HS Activities (n = 378)

Activity	Number of respondents	Median minutes per month, 2017 (range)	Median minutes per month, 2020 (range)
Attending medical appointments	352	65.5 (1-3050)	60 (0-2160)
Researching HS information	378	300 (10-3000)	240 (0-3000)
Wound care	384	300 (5-3000)	360 (0-3000)
Shopping for HS products	348	120 (10-3000)	60 (0-3000)
Participating in patient support groups	357	300 (2-3000)	120 (0-3000)

ii. EFFECTS OF HS ON WORK LIFE

Based on responses from 388 respondents from around the world, 78% of people with HS were working, 4% were in school and 13% were on disability/medical leave (**Table 4**).

HS has a negative effect on the ability to work and attend school for 81% of respondents, compared to 91% reported in 2017 (**Table 5**). Of the 415 respondents who shared information with us about their work and school absences, 59% of respondents missed at least 2 days of work and 16% missed more than 11 days of work every month for HS-related reasons (symptoms, medical appointments, etc.).

Table 4: Work/School Status (n = 388)

Status*	%
Employed full-time	44%
Employed part-time	16%
Self-employed	5%
Short-term disability	3%
Long-term disability	10%
On parental leave	1%
Unemployed	17%
Retired	4%
Student	4%
Stay at home parent	2%

Table 5. Effect of HS on Work Life (n = 415)

Effect	n (%)
No effect	78 (19%)
Slightly negative effect	165 (40%)
Very negative effect	172 (41%)

Respondents described various ways in which their abilities to attend work and school, and perform the tasks needed to be successful in their endeavours, were impacted by their disease. We have summarized these below.

Inhibits career progression

- Respondents must miss days, leave early due to drainage, pain and other symptoms
- Forced to go on disability
- Subject to demotions, layoffs and firings due to absences
- Often unable to assume more work responsibilities because of unpredictable nature of HS and debilitating symptoms during flares
- Absences due to physical and mental HS symptoms, as well as complications of treatment
- Working is even more challenging prior to a diagnosis since respondents do not have an official reason for their absences
- Considered lazy because of inability to perform certain work tasks

Impacts mental health

- Constant worry about odor, staining of clothes and office furniture
- Stress about the possibility of a flare often triggers actual symptoms

Necessary to adopt coping strategies

- Dark-coloured, loose clothing when possible (for some respondents, this required asking their employer to allow non-uniform regulated clothing)
- Showering immediately before going to work
- Carrying bandages to work, and taking time to re-administer dressings during shift

“When draining, I have to wear all black to cover up any leaking through bandages. I used to travel a lot and was terrified I would leak onto the car seats or in meetings. I work on a college campus and do a lot of walking when I travel and it is very painful to walk as my HS is primarily on my inner thighs and groin. I worry about odour. I have had bandages come off and slide down my pant leg and I find them on the floor at the office. Many times I just want to be home without clothing touching me or be able to soak numerous times a day.”

iii. EFFECTS OF HS ON SOCIAL LIFE

For 354 of 415 respondents (85%), HS has a negative effect on their ability to enjoy social interactions (Table 6). In the 2017 survey, we asked about the impact of this disease on patients' personal lives (the use of this term and not the more specific "social life" may have impacted responses) and found that 97% of respondents were negatively affected by HS.

Table 6. Effect of HS on Social Life (n = 415)

Effect	n (%)
No effect	61 (15%)
Slightly negative effect	179 (43%)
Very negative effect	175 (42%)

Respondents described the specific ways in which their social lives were impacted by HS, which have been categorized and listed below.

Inability to engage in social interactions

- Cancelling plans last minute due to symptoms is interpreted as being unreliable and leads to loss of friendship
- Cannot plan ahead for trips and other events
- Symptoms make it easy to forget about plans and events
- Work is so tiring and hard, it is often tough to force oneself to socialize after
- Sense of loss of a part of life...can't do "_____" anymore

Symptoms and side effects impact ability to be active

- Walking, sitting, cycling and most forms of exercise can be difficult or painful
- Cannot leave the house during a flare or a period of draining
- No water activities, which is most difficult in the summer months

Clothing options are restricted

- Must cover up, even in the summer
- Cannot wear "normal" pants
- No tight clothing

Impacts mental health and personal relationships

- Afraid to engage in most activities in case of pain, boil bursting, etc.
- Embarrassed by scars, and questions and judgement from other
- Fearful about the weather and how it will affect odour
- So worried and stressed about leakage, that going out does not seem worth it
- Have heard hurtful comments before and worried it will happen again

iv. EFFECTS OF HS ON FAMILY LIFE

For 283 of 415 respondents (68%), HS has a negative effect on family life (Table 7). Respondents reported that their condition had a severe impact on their abilities to participate in activities, on their financial status and on the emotional well-being of their families. This is summarized below.

Table 7. Effect of HS on Family Life (n = 415)

Effect	n (%)
No effect	132 (32%)
Slightly negative effect	189 (45%)
Very negative effect	94 (23%)

Impacts family activities

- Cannot participate in most family events
- Unable to do the activities that they identify as “parenting” (attend child’s events, carry/play with child, cuddle with child)
- For single parents, child is housebound if parent is having a flare

Impacts family finances

- Household income must be devoted to HS-related expenses such as medicine and clothes, and to pay for personal services when respondent is in hospital for surgeries

Impacts mental and emotional health of the whole family

- Children are concerned that they will also have HS
- When a patient experiences sadness and a loss of hope about their condition, that feeling affects the entire family
- Family feels worried about the future, particularly about the respondent getting worse or acquiring an infection
- The task of wound care often falls on the spouse, which causes feelings of embarrassment and vulnerability for the patient
- Some respondents report hiding their condition and its impact from their family members to avoid feeling like a burden

“There is a constant fear that I will have passed this awful thing to my children. I am not able to play with my children a lot of the times because of bleeding or pain and I’m not able to be as close to my son as I would like because of my skin.”

v. EFFECTS OF HS ON INTIMACY

HS has a negative impact on intimacy for the majority of respondents (87%) as shown in **Table 8**. When respondents described how their condition affected their ability to be intimate with their partner, they spoke of their partner's reaction to their symptoms, their own emotional state, how being intimate was impeded by the physical symptoms of HS, and about their strategies for coping.

Table 8. Effect of HS on Intimacy (n = 415)

Effect	n (%)
No effect	55 (13%)
Slightly negative effect	130 (31%)
Very negative effect	230 (56%)

Scarred by previous partner's reaction

- Received pitying, judgmental or hurtful comments about body
- Partner assumed boils along the groin area was an STI
- Partner was concerned HS symptoms were contagious
- Partner was turned off by the sores that opened during sex, leading to strong odour

Fear and anxiety about being intimate

- Self-conscious about body
- High levels of anxiety lead to intimacy avoidance
- Does not feel feminine
- Certain positions lead to visibility of the sores, causing embarrassment
- Fearful of beginning a new relationship and explaining HS

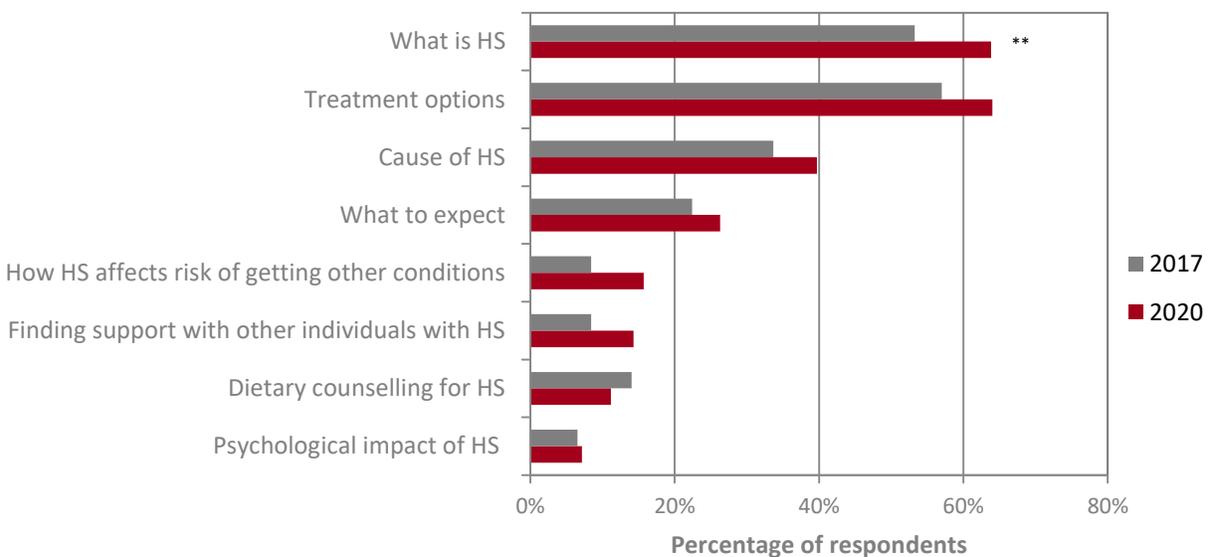
Physical

- Sex causes friction which can lead to a flare
- Inner thighs get inflamed
- Body is in too much pain to be touched
- Side effects of medications lower sex drive
- No longer finds him or herself attractive because of the weight gain caused by the inability to exercise

Section VIII: Knowledge of HS

Of the 350 respondents who provided us with information on which HS-related topics their HCP counselled them, more than 60% reported that they were told what the condition is and their treatment options (**Figure 31**). Compared to the 2017 survey results, a higher percentage of respondents were told about nearly every topic about which our survey inquired, indicating that healthcare providers are helping patients become more informed about their condition. However, less than 20% of patients received counselling from their HCPs on the psychological impact of HS, diet and how to find support from other individuals with HS. Receiving such information could positively impact their emotional and physical well-being.

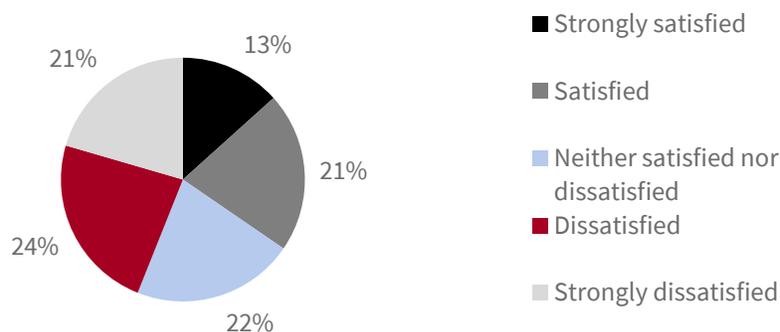
Figure 31: Topics for which an HCP Provided Information to the Patient (n = 350)



* Statistically significant difference (p<0.05)

Of 405 respondents, 45% were dissatisfied/strongly dissatisfied with their healthcare provider’s understanding of HS (**Figure 32**), suggesting a lack of confidence in the ability of HCPs to effectively counsel and treat this complex condition.

Figure 32: Satisfaction with Knowledge of HS (n = 405)

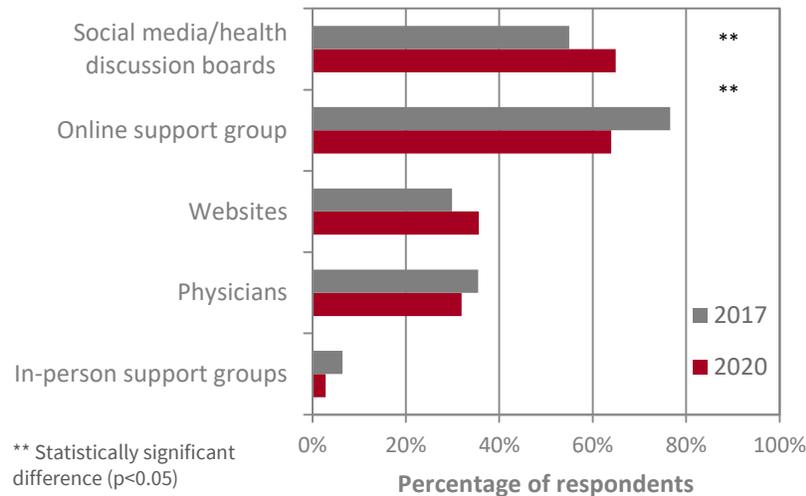


Section IX: HS-Related Patient Needs

We asked where patients turn to gain information about HS (Figure 33), and found that, similar to the results of the 2017 survey, respondents are still seeking insight and knowledge online. Less than 40% consider their HCP to be a primary source of HS information.

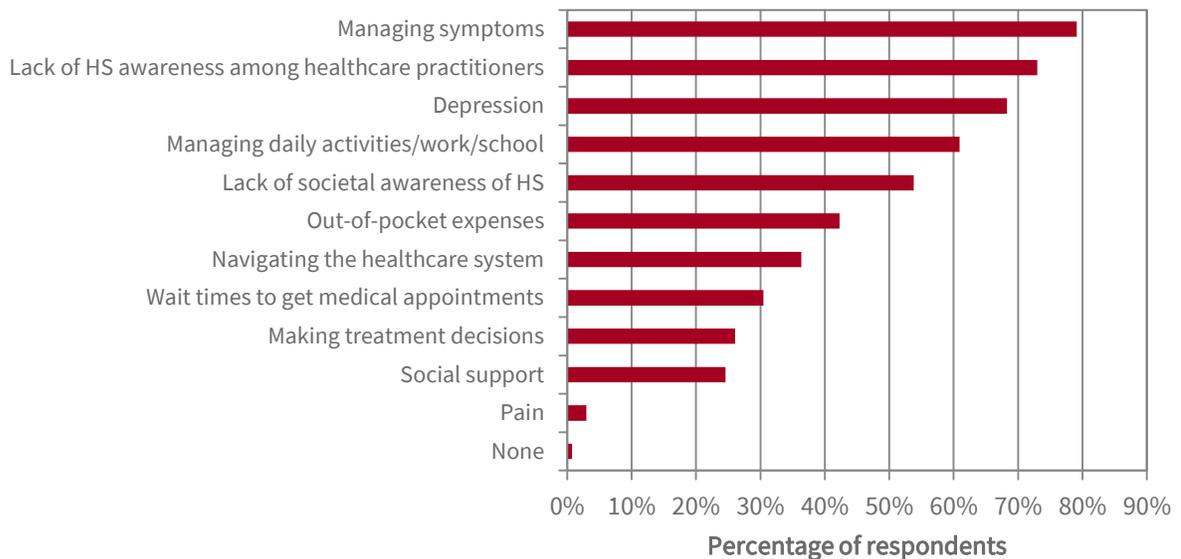
“The lack of support on this issue from my healthcare provider is why I think I’m failing to thrive, and developing really concerning anxiety. I’ve had to follow the medical advice given to other people that are on HS Facebook groups and also make drastic changes to my life based on available informational resources online.”

Figure 33: Primary Sources of Information on HS (n = 405)



Of 407 respondents, 99% revealed that they struggled with at least one aspect of having HS, and most had issues with three topics or more (Figure 34). As with the results of the 2017 survey, managing symptoms, lack of disease awareness among HCPs, and depression were topics that individuals with HS struggled with the most.

Figure 34: Areas of Struggle for Patients with HS (n = 407)



Section X: Advice for Newly Diagnosed Individuals

Respondents were asked whether they had advice to offer to those newly diagnosed with HS. They had various tips to help others come to terms with their new condition.

Seeking support is essential to being your best advocate

- ✓ Remember that you are not alone
- ✓ Join an online group
- ✓ Search for credible content. Read medical journals and reputable websites* to learn everything you can about this disease. You will likely need to educate your healthcare providers about HS
- ✓ Keep searching until you find healthcare providers that you trust
- ✓ Assemble a care team, and include a surgeon, social work, and dietitian in addition to a dermatologist
- ✓ Talk to your family and friends about it. Try not to hide

Practice regular self-care to optimize your HS treatment and minimize its impacts

- ✓ Remove hair from armpits and groin
- ✓ Wash the affected areas daily
- ✓ Explore dietary triggers and ways to get your digestive health in order. Dairy, sugar and gluten cause exacerbations for a lot of people. Explore different diets with a dietician or with your HCP
- ✓ Keep stress as low as possible
- ✓ Carry band-aids with you at all times
- ✓ Avoid tight clothes
- ✓ Heating pads may help

General advice

- ✓ Get started on treatments as soon as possible. Try not to ignore the symptoms as HS may worsen over time without treatment or surgery
- ✓ Remember that it will get worse before better
- ✓ Online support groups are great sources for different home treatments. Do not get discouraged by the fact that what works for one person will not necessarily work for you
- ✓ Familiarize yourself with the diseases that are often associated with HS
- ✓ Keep a diary and take pictures to track your process and help you identify triggers

*CSPA; HS Foundation; HS Online

“HS is painful, physically and emotionally. This is truly a fight of learning to live with your body. Remember that you have HS. Don't let HS have you.”

HSPE SURVEY TEAM

The survey team consisted of the following:

- Rachael Manion (Canadian Skin Patient Alliance)
- Dr. Raed Alhusayen (Sunnybrook Research Institute)
- Dr. Ilya Mukovozov (University of British Columbia)
- Stephanie Carter (HS Heroes)
- Dr. Jennifer Pereira (JRL Research & Consulting Inc.)

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- Zal Press (Patient Commando)
- Catherine Aguilar
- Denise Fixsen (hsconnect.org)
- Latoya Palmer (Hidradenitis and Me)
- Krystle Sutherland (HS Heroes)

REFERENCES

1. Alikhan A, Sayed C, Alavi A et al. North American clinical management guidelines for hidradenitis suppurativa: a publication from the United States and Canadian Hidradenitis Suppurativa Foundations: Part 1: Diagnosis, evaluation, and the use of complementary and procedural management. *J Am Acad Dermatol* 2019;81(1):76-90.
2. Jemec GBE, Kimball AB. Hidradenitis suppurativa: Epidemiology and scope of the problem. *Journal of the American Academy of Dermatology* 2015;73(Supp 1):S4-S7.
3. Ingram JR, Jenkins-Jones S, Knipe DW, Morgan CLI, Cannings-John R, Piguet V. Population-based Clinical Practice Research Datalink study using algorithm modelling to identify the true burden of hidradenitis suppurativa. *Br J Dermatol* 2017;178(4):917-24.
4. Janse IC, Deckers IE, van der Maten AD et al. Sexual health and quality of life are impaired in hidradenitis suppurativa: a multicenter cross-sectional study. *Br J Dermatol* 2016;176(4):1042-7.
5. Gooderham M, Papp K. The psychosocial impact of hidradenitis suppurativa. *J Am Acad Dermatol* 2015;73:S19-22.

6. Esmann S, Jemec GBE. Psychosocial impact of hidradenitis suppurativa: a qualitative study. *Acta Derm Venereol* 2011;91:328-32.
7. Lachaine J, Miron A, Shear N, Alhusayen R. The prevalence and incidence of hidradenitis suppurativa in Canada: results from a population-based survey. *Value in Health* 2016;19(3):A123.
8. Kim WB, Sibbald RG, Hu H et al. Clinical features and patient outcomes of hidradenitis suppurativa: a cross-sectional retrospective study. *J Cutaneous Med and Surg* 2015;20(1):52-7.
9. Canadian Hidradenitis Suppurativa Foundation. What is HS? <http://hsfoundation.ca/en/what-is-hs/> Accessed 2020-03-12.
10. Price KN, Thompson AM, Rizvi O, et al. Complementary and Alternative Medicine Use in Patients With Hidradenitis Suppurativa. *JAMA Dermatol* 2020;156(3):345–348.
11. Alavi A, Anooshirvani N, Kim WB, Coutts P, Sibbald RG. Quality-of-life impairment in patients with hidradenitis suppurativa: a Canadian study. *American Journal of Clinical Dermatology* 2015;16(1):61-5.
12. Alavi A, Farzanfar D, Lee RK, Almutairi D. The contribution of malodour in quality of life of patients with hidradenitis suppurativa. *J Cutan Med Surg* 2018;22(2):166-174.
13. Machado M, Stergiopoulos V, Maes M, et al. Depression and anxiety in adults with hidradenitis suppurativa: a systematic review and meta-analysis. *JAMA Dermatology* 2019;155(8):939-945.
14. Jalenques I, Ciortianu L, Pereira B, et al. The prevalence and odds of anxiety and depression in children and adults with hidradenitis suppurativa: systematic review and meta-analyses. *J Am Acad Dermatol* 2020; doi: 10.1016/j.jaad.2020.03.041.

APPENDIX: RESULTS OF THE 2017 HSPE SURVEY

In 2017, in collaboration with physician organization Canadian HS Foundation and patient group HS Aware, the CSPA conducted a literature search and survey of patients with HS in Canada and the United States. Our goal was to understand the patient journey from HS symptom onset to diagnosis and beyond.

Survey highlights:

- 167 surveys from individuals with HS
- 30% from Canada and 70% from United States
- 96% female
- Average age: 36 years
- Time from symptom to diagnosis: 9 years
- 80% of respondents had at least 1 misdiagnosis and an average of 3

Patient frustrations with their diagnosis journeys were reflected in their opinions of the healthcare system: nearly 70% were dissatisfied during this pre-diagnosis period. Respondents reported trying multiple medical, surgical and natural treatments, and lifestyle changes to prevent or treat HS symptoms, but most offered little to no improvement. Daily life has been affected for more than 90% of respondents, with symptoms having a detrimental impact on work/school life, resulting in 3 missed days per month. Additionally, 66% of respondents reported that they struggled with depression and anxiety.

Though respondents reported feeling a moderate amount of pain every day, most did not have a successful pain management regimen, with less than 1 in 5 indicating that their pain is very well-controlled.

From our findings, we developed several recommendations for the Canadian healthcare system:

- Increase awareness and education of HS among healthcare providers most likely to encounter patients with this condition (dermatologists, family physicians and emergency room physicians);
- Develop a coordinated multi-disciplinary approach for managing HS among healthcare providers;
- Provide funding for new treatments that show promise in managing symptoms, given that what is currently readily accessible has been extensively use with limited effect;
- Systematically offer resources and social support to patients with HS, to help manage the tremendous psychosocial impact of the disease; and
- Integrate pain management into the care plan for patients with HS.