Scarred for Life

A NATIONAL REPORT OF THE PATIENT EXPERIENCE LIVING WITH HIDRADENITIS SUPPURATIVA

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EXECUTIVE SUMMARY

Hidradenitis suppurativa (HS) is a chronic, debilitating skin condition that affects up to 4% of Canadians. Characterized by painful boils and malodorous discharge under the breasts, and under the folds of the stomach, groin, genital area and buttocks, HS impacts every aspect of a patient's life including their ability to maintain a career and personal relationships. Even apart from the tremendous medical burden, the psychological impact is high, with individuals suffering from depression and isolation.

The Canadian Skin Patient Alliance, a not-for-profit patient organization formed to help Canadians with skin conditions, collaborated with physician organization Canadian HS Foundation and patient group HS Aware, on the development of the Hidradenitis Suppurativa Patient Experience (HSPE) Survey. The HSPE Survey was disseminated to HS patient groups in January 2017 to elicit a stronger understanding of the patient experience. While this survey was tailored to Canadian patients to form a baseline of their healthcare progress, it was also open to US patients, given that many aspects of this condition are universal in nature, and unlikely to vary due to geography.

"The most difficult part of finding a diagnosis was having to access three general practitioners before one diagnosed my HS correctly. It was embarrassing as my HS is in my pelvic area. I felt alone and scared. It was so painful, and I felt dismissed by doctors whose treatments for misdiagnoses didn't work."

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
- Average age at diagnosis: 32 years

In Canada, the route to diagnosis was arduous, involving multiple appointments with healthcare providers (HCPs), misdiagnoses and failed treatments. Eight out of 10 individuals had at least one misdiagnosis for HS, and three on average.

Satisfaction with the healthcare system was extremely poor during the search for a diagnosis, but improved considerably once the patient's symptoms were identified as HS and the individual was treated for this condition.

Although patients try multiple medical and natural treatments, as well as avoidance of behaviours, to prevent or treat HS symptoms, most offer little to no improvement.

- Average monthly out-of-pocket expenses related to HS symptoms = $258
- For 91% of individuals, symptoms had a detrimental impact on work/school life, resulting in 3 missed days per month
- Most had moderate pain on a daily basis, but were mainly self-treated

Instead of turning to HCPs as their primary source of HS information, individuals go online to receive immediate support from others who are also plagued by this condition, and who have accumulated considerable knowledge on the course of this disease based on first-hand experience. HS patients struggle with managing symptoms and dealing with depression and anxiety.

"I'm embarrassed all the time and can't even tell friends or family because of the shame. Even though I know it's not a hygiene issue, I think most people think it is. It's humiliating. Please find a cure."

HS is a complex disease that has a debilitating effect on patient quality of life, both physically and mentally. Based on survey findings, we have the following recommendations to Canada's 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 used 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.

It is our hope that this report will serve as the impetus for greater awareness of the journey lived by HS patients, and care and treatment improvements for those with HS, as well as baseline data to measure progress towards these goals in the future.

BACKGROUND

Hidradenitis suppurativa (HS) is a chronic, immune-mediated skin disease, characterized by painful recurrent lesions in the armpits, groin, between the buttocks, and/or under the breasts, and often accompanied by purulent discharge and unpleasant odor. These can in turn result in sinus tracts, scarring, strictures, or fistulas. Given that the symptoms of HS can be very unsightly, painful and embarrassing, various studies have shown that this disease typically has a more detrimental impact on patient quality of life than other dermatological conditions.[1,2] Patients with HS often experience a psychosocial and medical burden that impedes their ability to conduct daily activities on their own. Additionally, the symptoms of HS interfere with both their work-life and their personal relationships.[2]

Although HS prevalence was always considered to be around 1% in Western countries, a recent large Canadian study found this condition to affect approximately 3.8% of the general population.[3] This supports the theory that HS is commonly underestimated, likely at least partly due to complexities with diagnosis. The first symptoms appear on average at 24 years old and at 28 years old in diagnosed and self-reported groups, respectively.[4] The average Canadian patient with HS will see five physicians with over 17 visits spanning eight years before being diagnosed.[4] Even after diagnosis, navigating provincial health systems and finding optimal care continue to be challenging. Many therapies and treatments that are used to manage HS have limited effects or significant side effects. Although surgery may provide some relief, it is also accompanied by an increased risk in scarring and infection. Additionally, considerable costs related to HS may not be publicly funded, and therefore patients must rely on private insurance or pay out-of-pocket.

A recent Ontario study of 80 individuals with HS found results consistent with prior epidemiological characterizations: the patient base is predominantly female, were diagnosed as young adults (under 35 years), were diagnosed by a dermatologist, and were diagnosed accurately after more than a year of symptoms.[5]

In a US study of healthcare utilization, those with HS had higher healthcare costs than other dermatological patients, mainly due to costs related to hospitalization. Nearly 16% of individuals with HS were hospitalized in the last three years while 27% had visited the emergency room.[6]

"My HS is so bad that I have been unable to function in an office setting for over 3 years. [It's] extremely hard to concentrate when you feel like your flesh is being ripped apart."

The healthcare journey involves the stages from first symptom to diagnosis, and access to medical and surgical treatment once HS has been identified. In Canada, healthcare is a provincial responsibility, which can result in inequities in access to medical care and treatment across the country. To date, there has been a lack of research

seeking to comprehensively describe the experiences of individuals in Canada with HS, and to identify gaps in the healthcare system with respect to diagnosis and treatment of this condition.

The Canadian Skin Patient Alliance (CSPA) conducted a literature search and survey of patients with HS (formally diagnosed or self-diagnosed) to answer critical questions regarding gaps in patient care, and deficiencies in provincial healthcare systems. The focus of this research was to describe the patient experience from diagnosis and beyond, including path to diagnosis, symptom control, experience with treatments, healthcare utilization, patient needs, and impact on quality of life.

The findings of this study will serve as the baseline measure for HS care in this country, and will inform future work conducted by the CSPA, physician organization Canadian HS Foundation, and patient group HS Aware to improve the patient experience for those with HS. In upcoming years, this report will provide a needed comparison as we move forward and track the progress of our healthcare system in improving patients' access to effective care and treatment for HS.

• • •

"The most difficult part is not knowing why you're suffering from HS, only to have the doctors tell you to lose weight, stop smoking (even when you are a non-smoker) and to use more antibacterial soap. The sense of shame that goes along with this disease is overwhelming."

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METHODS

The CSPA developed the online Hidradenitis Suppurativa Patient Experience (HSPE) survey in collaboration with the Canadian HS Foundation and HS Aware. The HSPE Survey was extensively reviewed and pilot-tested by two executive members of HS Aware, who provided patient perspective, and assisted with revisions for clarity and comprehensiveness.

Survey eligibility criteria:

- Residing in Canada or the United States
- Having either a self-diagnosis or formal diagnosis of HS

The survey was created in Survey Monkey (https://www.surveymonkey.net/) and designed to be completed within 25 minutes.

HSPE survey dissemination

We disseminated the electronic HSPE Survey link through various means in order to access a large cross-section of individuals with HS:

- CSPA's website/Twitter/Facebook
- HS Aware's Twitter/Facebook
- Canadian HS Foundation
- Patient Commando's Twitter/Facebook
- Facebook pages of HS patient groups

We encouraged respondents to share the link with others who may be interested in providing their voice. The HSPE Survey was open from January 16th to February 1st, 2017.

To supplement the survey data on time spent on HS-related activities, we obtained data from the Canadian Institute for Health Information (CIHI) on healthcare utilization related to HS from 2010 to 2015.

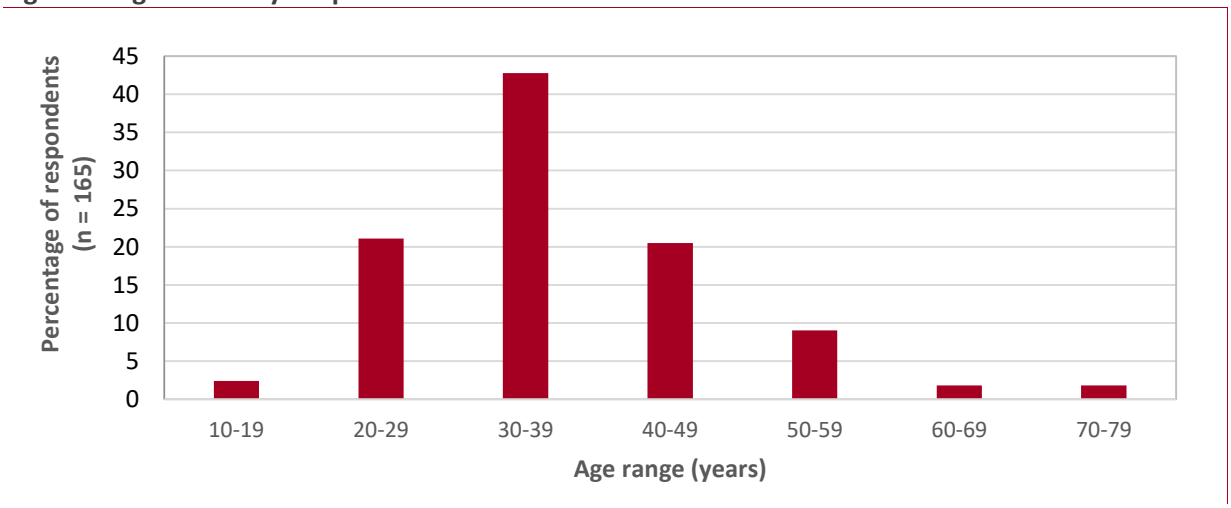
RESULTS

In total, surveys were received from 167 eligible respondents. One-hundred and fifty-one individuals (90.4%) had been formally diagnosed with HS by a healthcare provider (HCP) while the remainder were self-diagnosed only.

i. DEMOGRAPHICS

The majority of eligible respondents were female (95.8%), and the average age was 36 years with a range of 17 to 75 years. Most were under the age of 40 years (Figure 1). These demographics differ slightly from previous studies (for example, HS is thought to affect female and males at a 3:1 ratio). Such differences may be reflective of survey distribution via on-line support groups.

Figure 1: Age of Survey Respondents



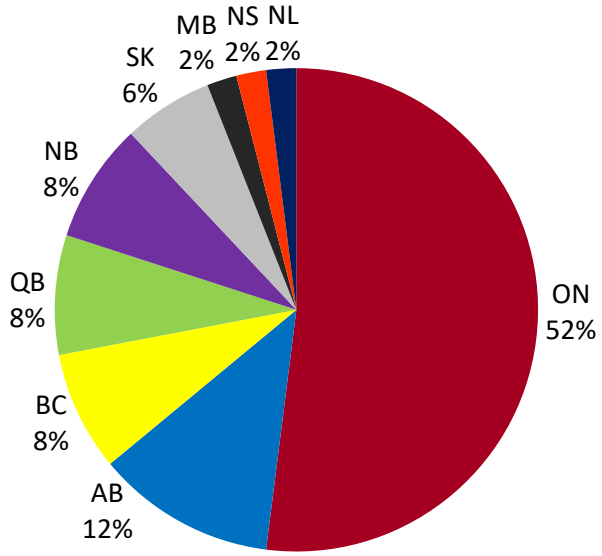
Of all respondents, 50 were from Canada (29.9%), with more than half residing in Ontario (Table 1, Figure 2). Similarly, these results could be reflective of how the survey was distributed as there are no current data demonstrating that the HS prevalence rate is higher in Ontario.

Table 1: Provincial Distribution of Surveys*

Province*	Number of surveys
Ontario (ON)	26
Alberta (AB)	6
British Columbia (BC)	4
New Brunswick (NB)	4
Quebec (QB)	4
Saskatchewan (SK)	3
Manitoba (MB)	1
Newfoundland (NL)	1
Nova Scotia (NS)	1
Total	**50**

*No surveys were received from provinces and territories not listed

Figure 2:
Provincial Distribution of Surveys, by Percentage



Section I: Seeking a Diagnosis in Canada's Provincial Healthcare Systems

We asked respondents from Canada about their journey through their provincial healthcare system while seeking a diagnosis for HS-related symptoms.

i. HEALTHCARE UTILIZATION

To better understand patient interactions with HCPs, we requested feedback on the number of *different* HCPs they saw during this pre-diagnosis period (Figure 3).

- Ninety percent of respondents visited a

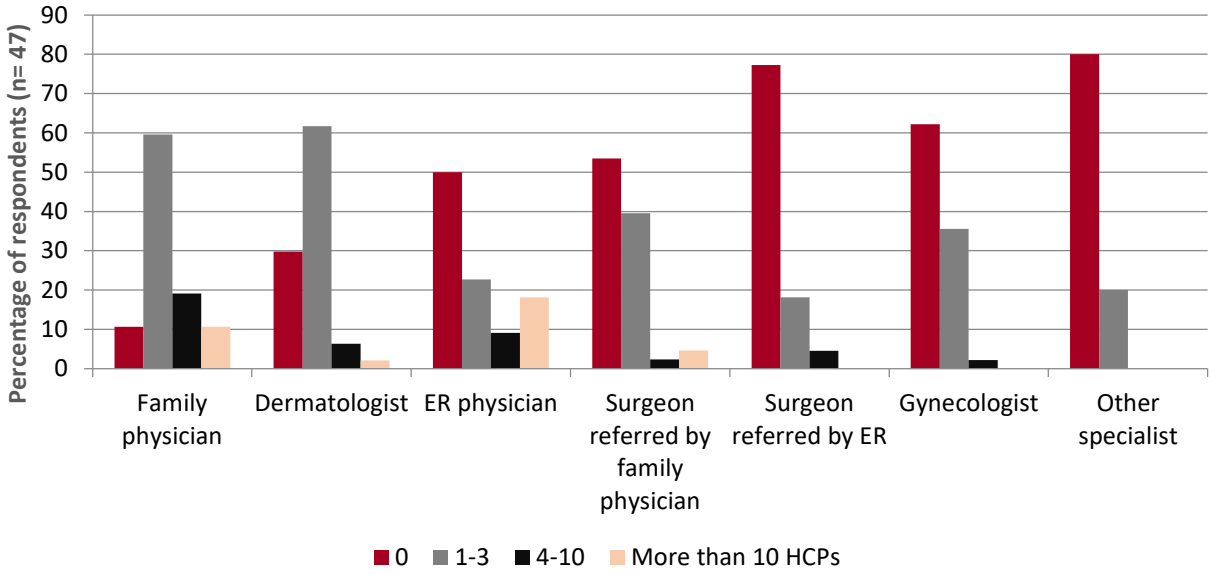
"They did their best but when physicians lack knowledge, they guess or experiment.

Twelve years of that took its toll."

family physician regarding symptoms, and 49% saw more than three
- The majority (61%) visited 1 to 3 different dermatologists
- Half of all respondents consulted with emergency room (ER) physicians for HS symptoms, and of these, 36% consulted with more than 10 ER physicians
- Only 23% were referred to a surgeon during their ER visit for HS symptoms, while 47% consulted with a surgeon based on a referral from their family physician
- Gynecologists were seen during the pre-diagnosis stage by 36% of respondents

Other specialists, primarily infectious disease specialists and endocrinologists, were seen by 20% of respondents.

Figure 3: Number of Different HCPs Consulted for Symptoms of HS Prior to Diagnosis

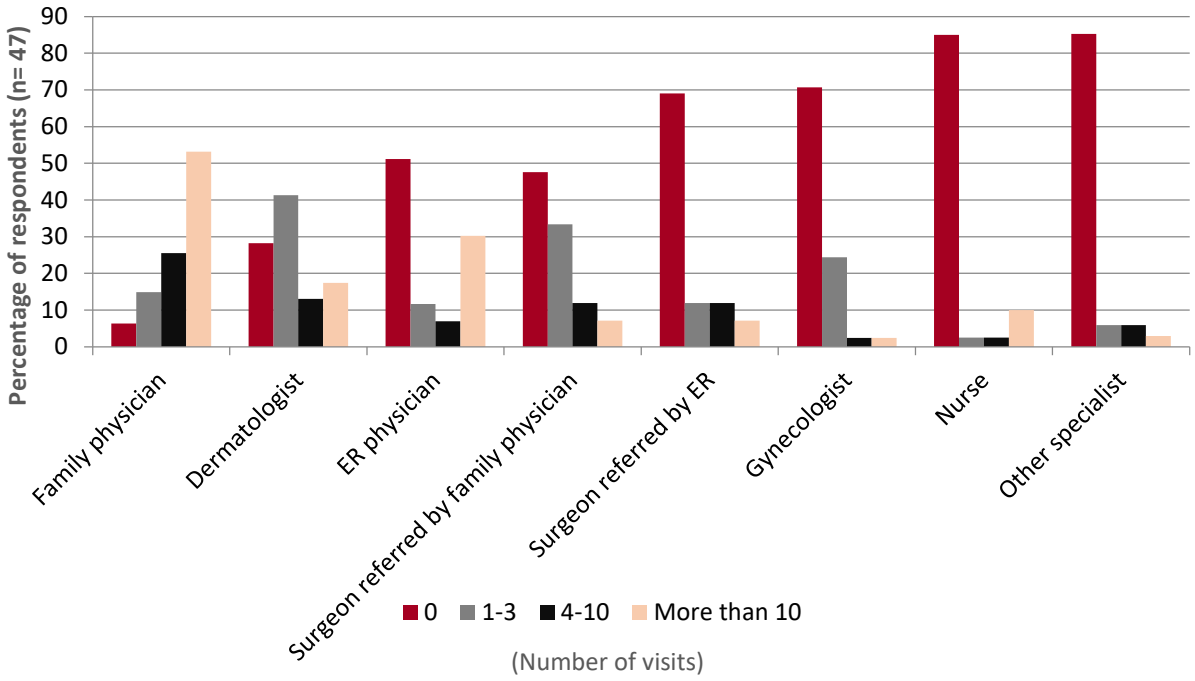


During the pre-diagnosis stage, respondents sought medical care repeatedly for symptoms of HS (Figure 4).

"Doctors always made me feel like it was my fault. That I was unclean. That I did not take care of myself or wash myself properly."

- Family physicians were seen frequently, with 79% of patients making at least four visits, and 53% visiting 10 or more times
- 72% visited a dermatologist at least once, and 17% made 10 or more visits
- 30% made 10 or more trips to the ER
- 10% saw a nurse for care 10 or more times
- 3% of patients had medical visits with other specialists (e.g., endocrinologists, gastroenterologists)

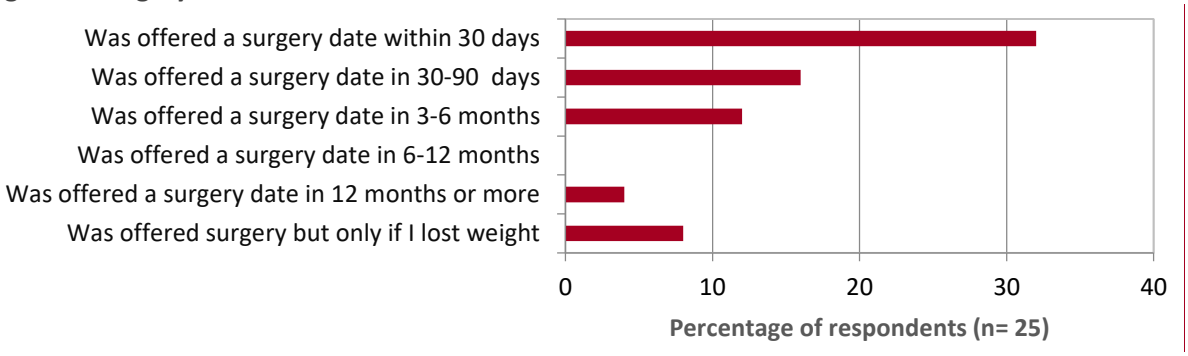
Figure 4: Number of Different Medical Visits for Symptoms of HS Prior to Diagnosis



ii. WAITING TIMES

Prior to receiving a diagnosis, patients from Canada often had lengthy waits for consultations with specialists. The median amount of time until meeting with a referred dermatologist was 180 days, although the range was 5 days to 4,015 days (n= 43). While the majority of respondents did not consult with a surgeon for treatment of symptoms, those that did (n= 20) waited for a median time of 150 days, with a range from 7 to 3650 days.

Figure 5: Surgery Wait Times

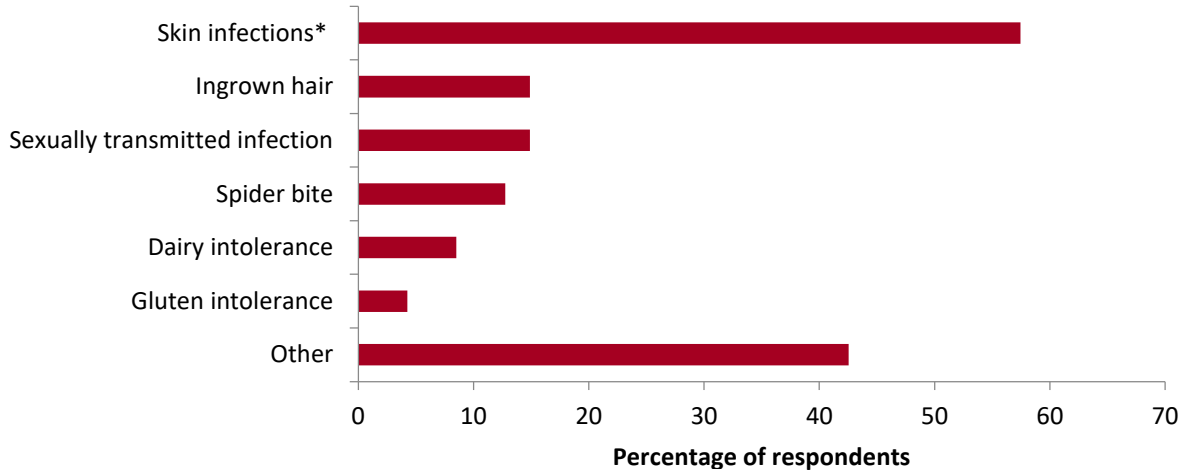


For those who reported on their consultations with surgeons, 7 (28%) were not offered surgery. Of the remaining patients, there were further delays for surgery dates (Figure 5). Additionally, two respondents were informed that they would only be offered surgery if they lost weight.

iii. MISDIAGNOSES

Prior to receiving a diagnosis of HS, 78% of respondents from Canada received at least one misdiagnosis, and up to seven. The average rate was three misdiagnoses per person.

Figure 6: Percentage of Respondents with Misdiagnoses



*Includes staphylococcus infection, furunculosis and MRSA

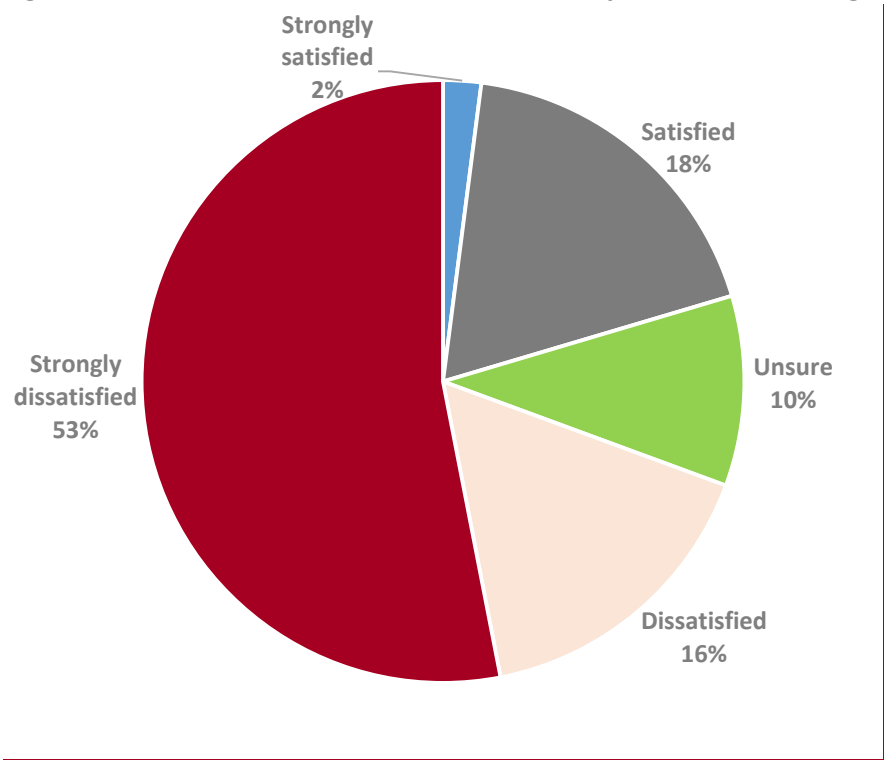
The most common misdiagnosis was staphylococcus infection which was reported by 37% of respondents (Figure 6). Forty-two percent indicated that they had been given a diagnosis that was not listed. Of these, the most common were "unhygienic" (n = 3) and "boils" (n = 4).

iv. SATISFACTION WITH THE HEALTHCARE SYSTEM

"HS is so painful and so complex... and hardly any doctors out there know it exists."

The route to HS diagnosis was often difficult and frustrating, as illustrated by Canadian respondents' satisfaction with their provincial healthcare system during this period. Of 49 respondents, 26 (53%) were strongly dissatisfied with their experience, and an additional 8 (16%) were dissatisfied (Figure 7).

Figure 7: Satisfaction with Provincial Healthcare System, while Seeking Diagnosis

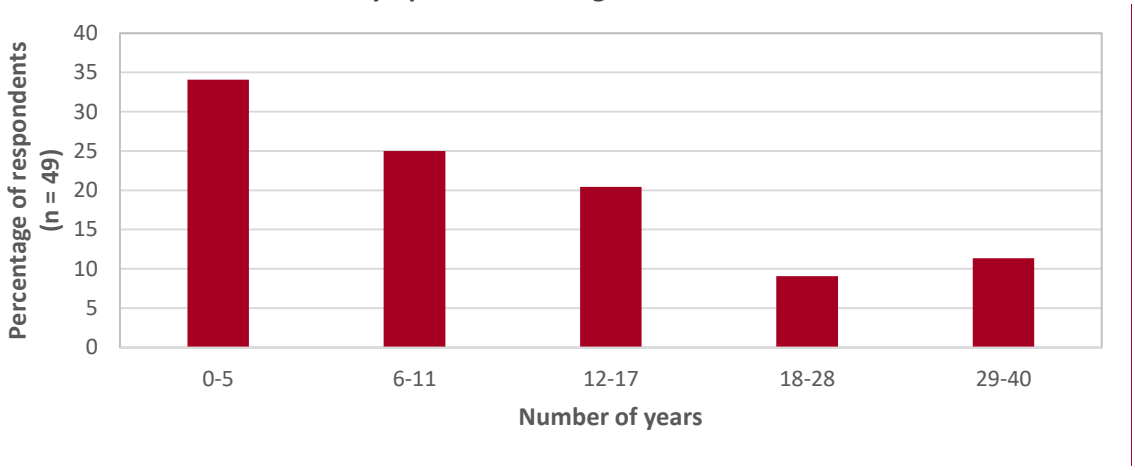


Section II: Diagnosis and Management of HS

i. DIAGNOSIS OF HS

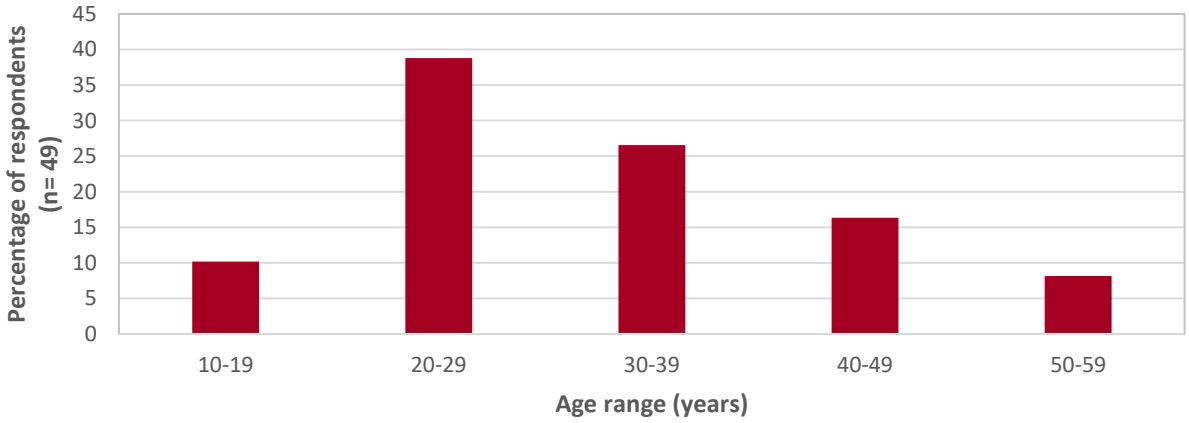
The path to diagnosis with HS varied considerably for patients from Canada, with a median time from first symptom to diagnosis of 9 years (range of less than one year to 40 years, Figure 8).

Figure 8: Number of Years from Symptom to HS Diagnosis



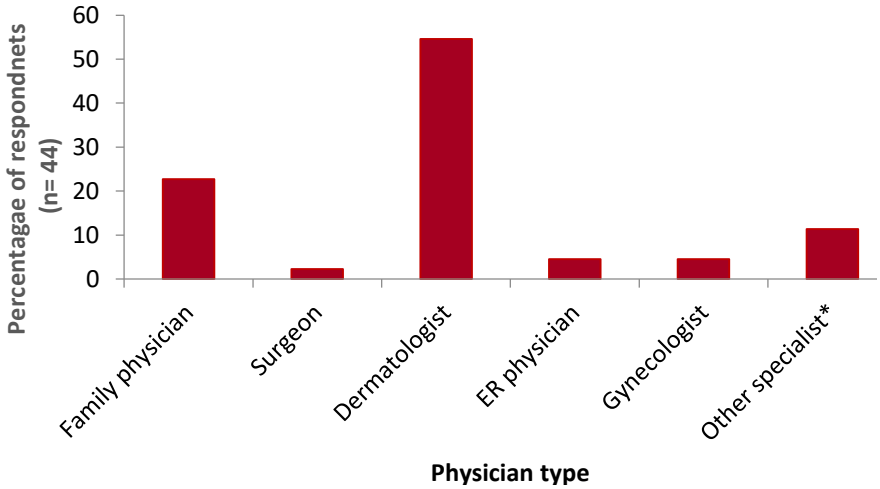
The average age at diagnosis for the 49 respondents from Canada was 32 years, with all respondents diagnosed between 12 and 55 years of age (Figure 9).

Figure 9: Age of First Diagnosis of HS



The diagnosis of HS was most commonly made by the dermatologist (55%) or family physician (22%). In addition to surgeons, ER physicians and gynecologists, other specialists including infectious disease specialists also provided diagnoses (Figure 10).

Figure 10: Physician Type who Provided First Diagnosis of HS



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

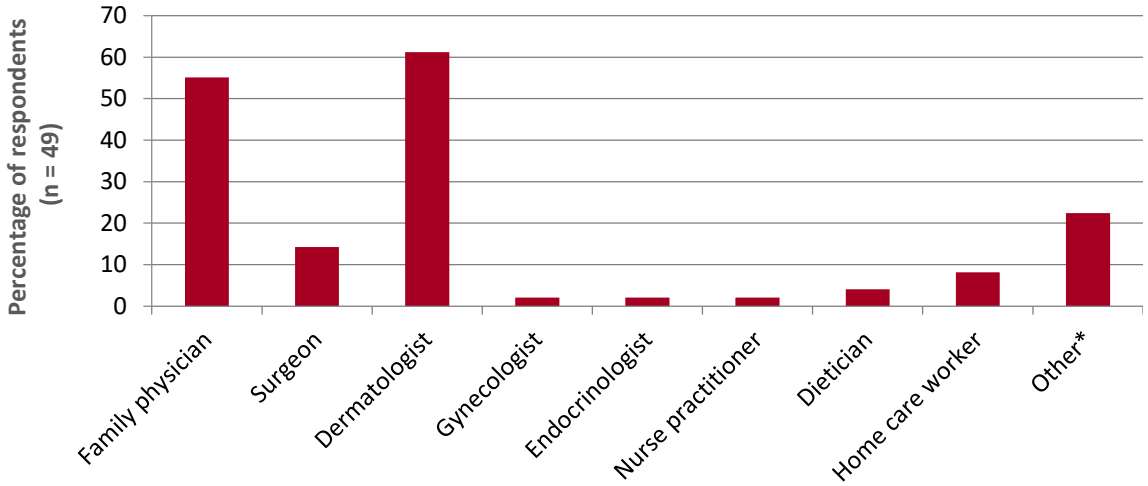
"The most difficult part of getting a diagnosis is just getting a doctor to look past weight and actually listen to ALL of your symptoms. Not just looking at these "lesions" and saying that they are classic MRSA or Staph lesions."

ii. CURRENT HEALTHCARE TEAM FOR MANAGEMENT OF HS

Respondents from Canada currently have at least one and up to three HCPs in their circle of care for management of HS symptoms. Dermatologists were the most common HCP, followed by family

physicians and surgeons (Figure 11). Of respondents, 25% indicated that others not listed were part of their care team; the most common "other" was "self".

Figure 11: HCPs Included in Current Care Team for HS Symptoms



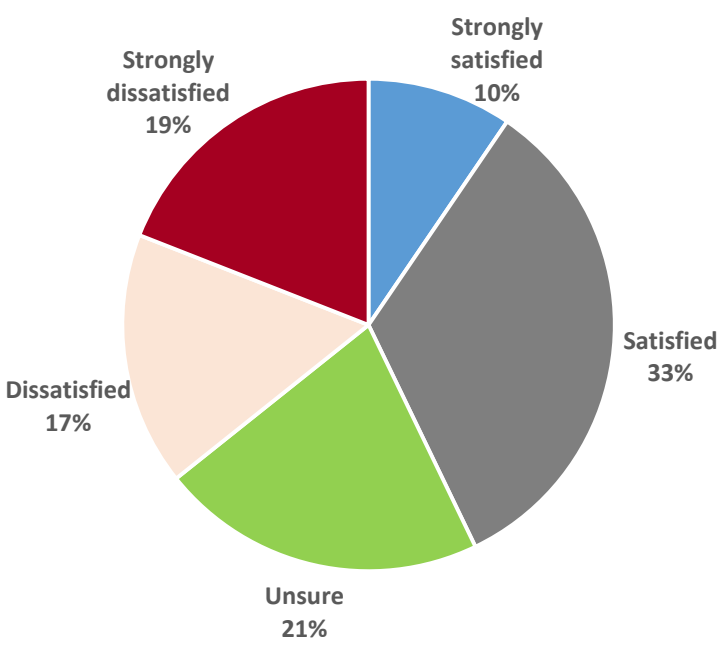
*Self, family, online support groups, infectious disease specialist, pain management specialist, emergency room physician, rheumatologist

iii. SATISFACTION WITH CURRENT CARE FOR HS

Satisfaction with their current state of care for HS was found to be high compared to when respondents from Canada were still waiting for a proper diagnosis. Of 42 respondents who answered this question, 36% were dissatisfied or strongly dissatisfied with their care, while 43% were satisfied or strongly satisfied (Figure 12). It is difficult to differentiate how much of this improvement is due to better care, finally accessing HCPs who are familiar with HS, or simply alleviating the frustration that results from not having a name for a debilitating condition. However, it is positive to see that individuals were more satisfied with their care than they were during their journey to diagnosis.

"Now that I have a name for this disease, my new doctor has been incredible in helping me to manage."

Figure 12: Current Satisfaction with Provincial Healthcare System for Treatment of HS



Section III: Cost and Effectiveness of Treatments to Prevent and Control HS Symptoms

We asked respondents about their monthly HS-related expenses, and noted a large variation in costs (Table 2). Of 37 Canadians who reported their costs, the median cost was $258 per month for treatments, with a range of $0 to $7,100. This cost was a combination of various purchases such as medications, other symptom treatments, preventative measures, and management of the emotional impact of HS.

Nineteen individuals from Canada provided information regarding their health insurance coverage for their medications related to HS. More than one-quarter were covered for 20% or less of their costs. Six individuals (32%) had insurance that covered 60-80%, and the remaining 8 individuals (42%) were fully covered for HS medication costs.

Patients have clearly tried multiple medications, at-home treatments, avoidance of solutions/behaviours/lifestyle choices, as well as surgical treatments and other therapies (Figure 13) to prevent symptoms of HS. This experimentation is no doubt a reflection of the severity of their exacerbations.

Antibiotics and OTC drugs had been commonly used, likely due to fairly easy accessibility. However, for the majority of patients, the result has been either very mild improvement or none at all. Less than 30% have tried biologics, oral retinoids and corticosteroids for HS, potentially due to accessibility hurdles, making it difficult to assess their performance.

Dietary and lifestyle regimens appeared to be the most effective of at-home treatments for symptom control, though the majority of respondents did not find a strong improvement.

Avoiding specific solutions and behaviours is also commonly attempted, again showing promise for only a minority of patients.

Surgical treatment offered the most benefit in terms of treatment symptoms of HS. Stress management was also considered to be helpful to some patients.

Figure 13: Effectiveness of Treatments to Prevent and Manage HS Symptoms

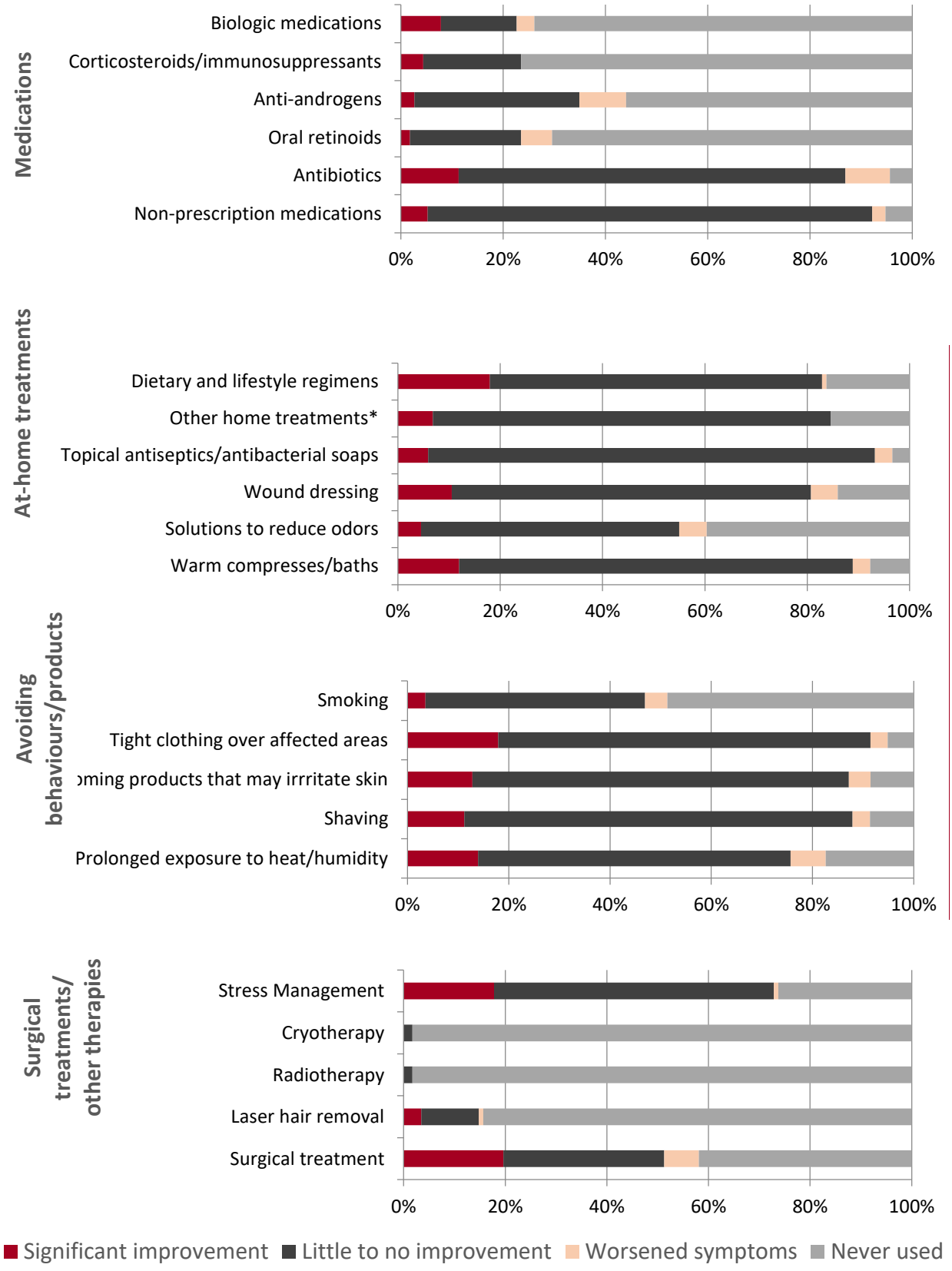


Table 2: Monthly Out-of-pocket Costs per HS Treatments and Therapies*~

Item[1,2]	Median Monthly Cost ($)	Range ($)	n
Medications			
Non-prescription drugs[3]	30	10-500	28
Prescription drugs[4]	25	5-1000	17
Symptom prevention			
Topical antiseptics/antibacterial soaps	23.5	5-150	26
Dietary & lifestyle regimens	100	20-1000	15
Smoking cessation	60	24-200	5
Undergarments	20	10-500	13
Laser hair removal	1000	70-1500	5
At-home symptom treatment			
Skin products to reduce odors	20	5-300	17
Wound care supplies/drainage	30	5-500	17
Wound dressing**	25	10-200	20
Warm compresses/hydrotherapy	30	4-300	17
Other home treatments[5]	20	4-500	27
Psychological impact of HS			
Stress management	$80	5-500	10
Anxiety & depression care	65	10-300	16

*n varies per row because not every respondent uses all treatments and therapies; those who did not use a specific treatment/therapy or abstained from responding were excluded in the calculation of monthly cost.
~Other costs may be covered through a public or private insurance plan
[1]No respondents indicated payment for surgical treatment, radiotherapy or cryotherapy
[2]Two respondents stated that they pay for biologic drugs but their extremely low costs ($1 and $40) indicate that they must be covered by a private insurance plan
[3]Tylenol, Aspirin, Motrin, Advil, hydrocortisone cream, etc.
[4]Antibiotics, retinoids, hormone therapy, immunosuppressants, corticosteroids, metformin, etc.
[5]Vicks, Medihoney, baby powder, Epsom salts, bleach, zinc cream, etc.
**Does not include wound care costs after surgeries, which can be significantly higher

Section IV: Impact of HS on Daily Life

i. TIME SPENT ON ACTIVITIES RELATED TO HS

All respondents were asked how much time they spend on activities related to HS (Table 3). The results demonstrate that a substantial amount of time (15-20 hours per month) is spent on management of symptoms, and self-education about this condition. Additionally, the data indicate that there are a small group of patients (likely those with moderate to severe HS), that are spending significant time (more than 20 hours a month) on medical appointments. This does not include additional time off work, school or personal activities due to symptoms of HS.

Table 3: Time Spent on HS Activities

Activity	n	Median minutes per month (range)
Attending medical appointments	98	65.5 (1-3050)
Researching HS information	100	300 (10-3000)
Wound care	95	300 (5-3000)
Shopping for HS products	77	120 (10-3000)
Participating in patient support groups	57	300 (2-3000)

"Flare-ups are random so you cannot predict when one is coming or how bad it will be. I no longer work. I stay at home [because] explaining the disease to employers is almost impossible. It takes up to 4 days for a flare to heal and most times it takes longer than that."

ii. HEALTHCARE UTILIZATION – DATA FROM THE CANADIAN INSTITUTE FOR HEALTH INFORMATION

To supplement the survey data on time spent on activities related to HS, we obtained data on healthcare utilization from the Canadian Institute for Health Information (CIHI) from provinces which provide full or partial data to CIHI. For privacy reason, CIHI cannot provide data for counts between 1 and 4; this has been denoted with an asterisk on the following graphs. CIHI does not have access to provincial data from Quebec, and that data from BC were not available.

Overall, the number of ER visits documented as related to HS is fairly low across all provinces (Figures 14a and b). Given that 30% of patients with HS report visiting their ER for HS symptoms more than 10 times prior to diagnosis (Figure 4), this Figure further demonstrates the lack of HS awareness among HCPs.

There appears to be a trend of increasing HS-related ER visits from 2010 to 2015, both for HS as the most responsible diagnosis (reason for visit, Figure 14a) or as a noted comorbidity (Figure 14b). It is not possible to conclude if this is due to an increased awareness of the disease (most likely), higher prevalence of HS in later years, more exacerbations of HS in a population with stabilized prevalence, or changes in

disease definition coding or reporting. Although HS-related appointments occurred in each of the included provinces, only partial data was provided for Manitoba, Nova Scotia, Prince Edward Island and Saskatchewan so no conclusions can be made beyond that there are patients living with HS in these provinces. Higher numbers are seen in Alberta and Ontario, no doubt partially due to their larger overall populations. These are also the only two regions where patients visited the ER with HS already diagnosed (Figure 14b), which may be a reflection of both easier access to dermatologists and the presence of academic centres within these provinces.

Figure 14a: ER Visits for which HS is *Most Responsible Diagnosis*

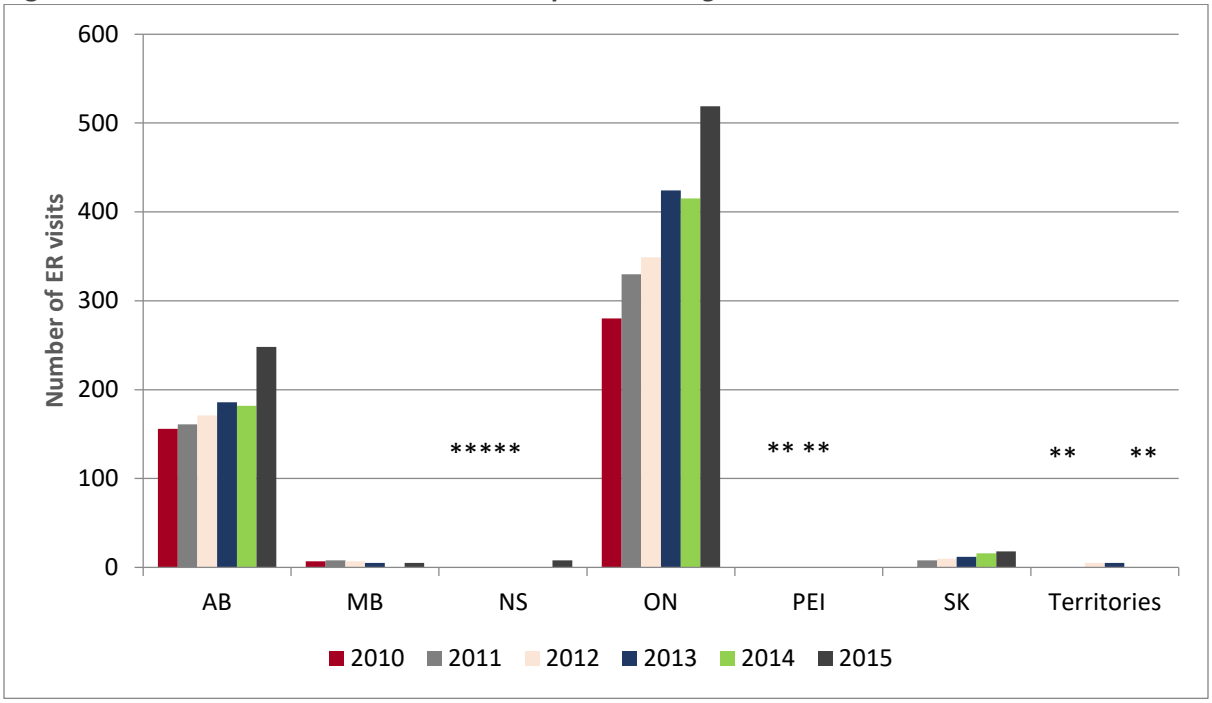
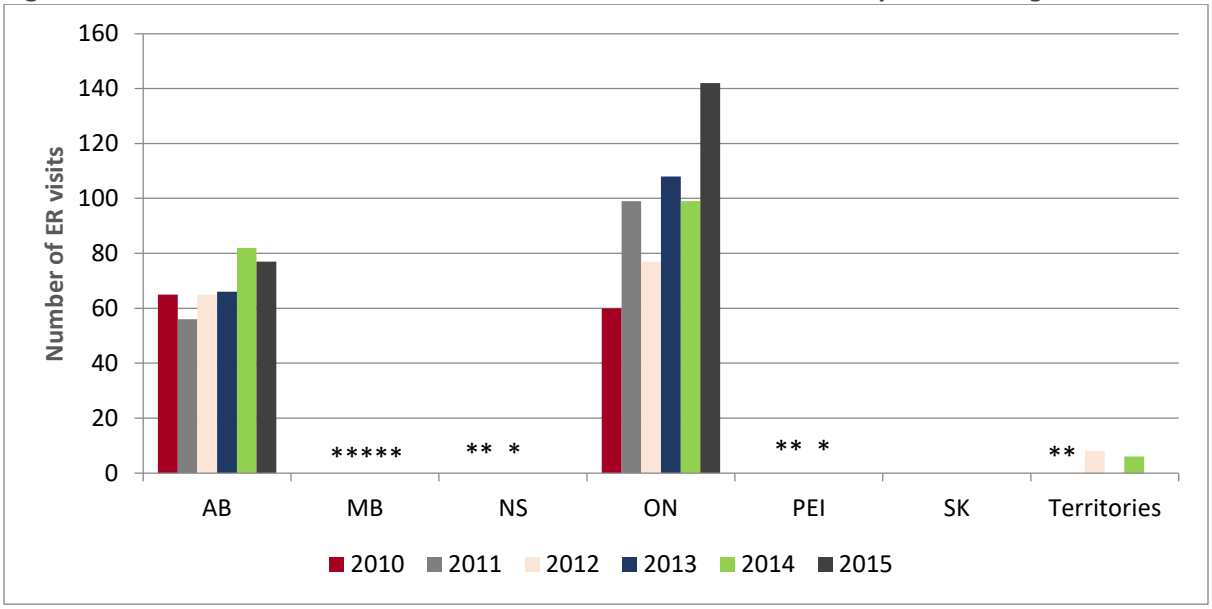


Figure 14b: ER Visits for which Patient's HS is Noted but not as *Most Responsible Diagnosis*



Although there were hospitalizations related to HS in every province, Ontario in particular had substantially high numbers (Figures 15a and b), as Canada's most populous province. While there are upward trends in hospitalizations where HS is listed as a pre-admit comorbidity, no trend is evident for hospitalizations where HS is the most responsible diagnosis. Instead, the numbers have varied over the years.

There are no data for HS as a post-admit comorbidity which is reasonable given that it is not considered to be a condition that results from an in-hospital complication.

Figure 15a: Hospitalizations where HS was a *Pre-admit Comorbidity*

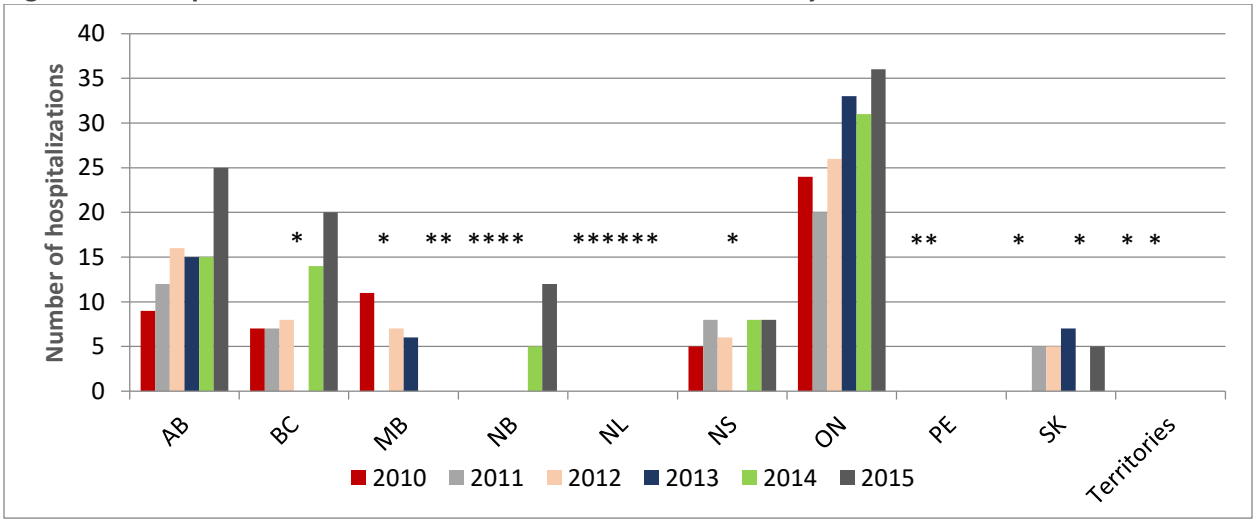
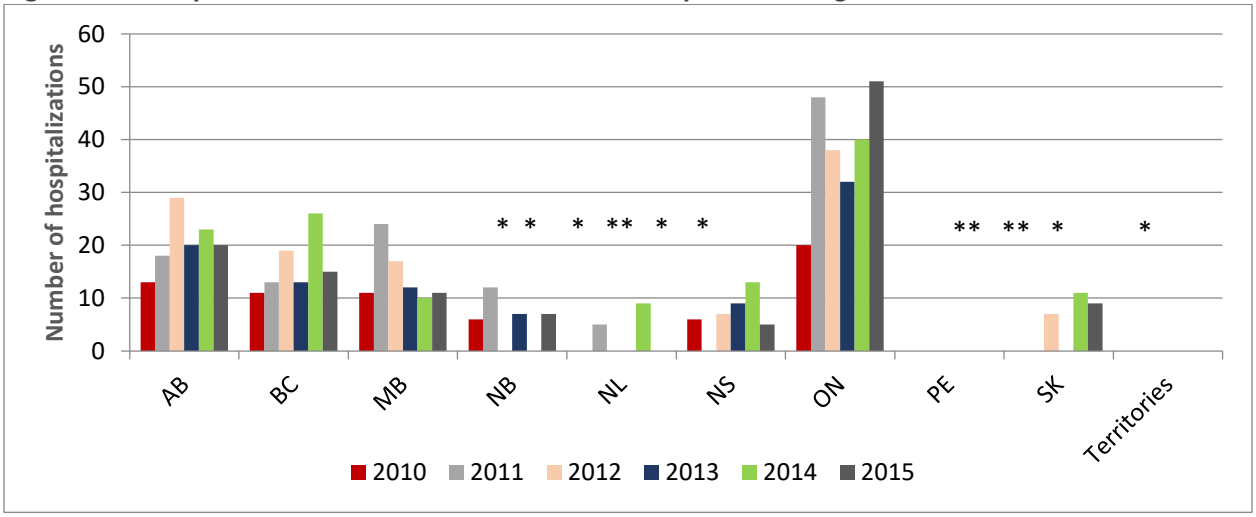


Figure 15b: Hospitalizations where HS was the *Most Responsible Diagnosis*



The duration of hospital stay associated with HS varies considerably (Figures 16a and b), no doubt influenced by the main hospital indication (in the case of HS as a pre-admit comorbidity) or the HS-related symptom for which they are seeking treatment in-hospital.

Figure 16a: Total Number of Inpatient Hospital Days where HS was *Pre-admit Comorbidity*

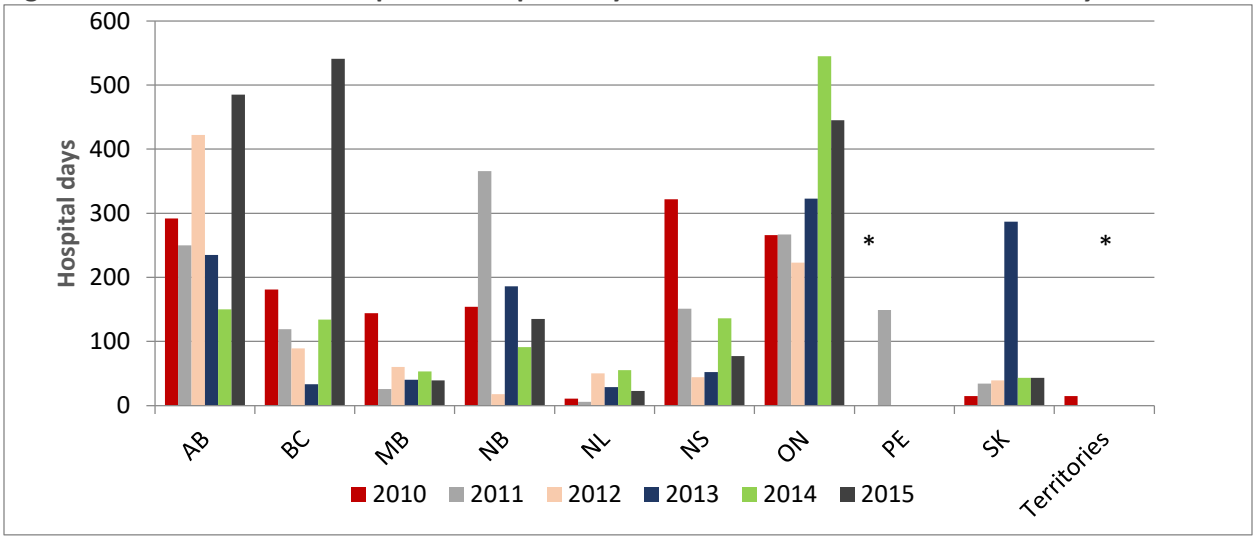
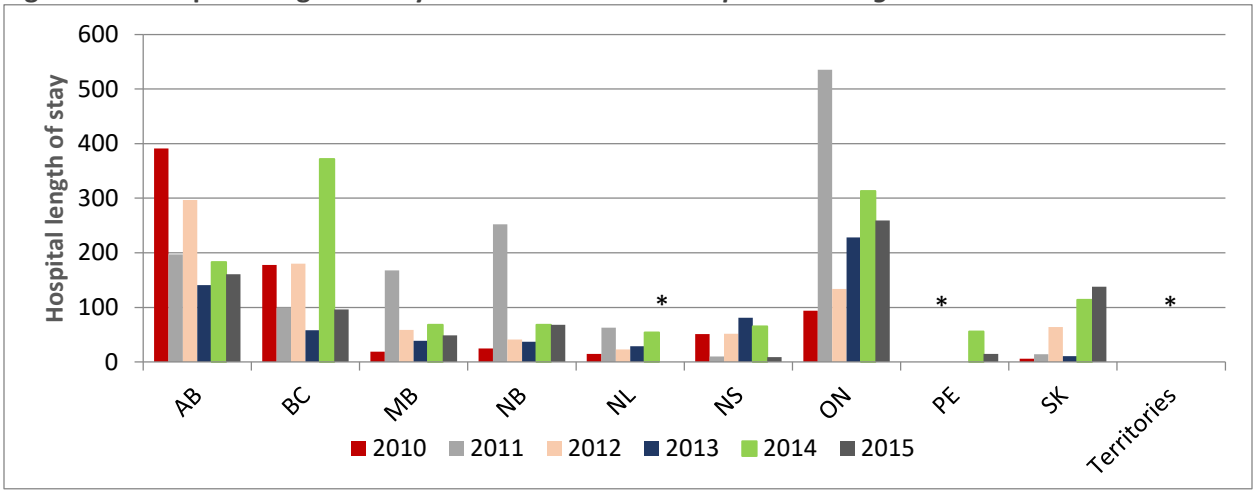


Figure 16b: Hospital Length of Stay where HS was *Most Responsible Diagnosis*



iii. EFFECT OF HS ON WORK AND PERSONAL LIFE

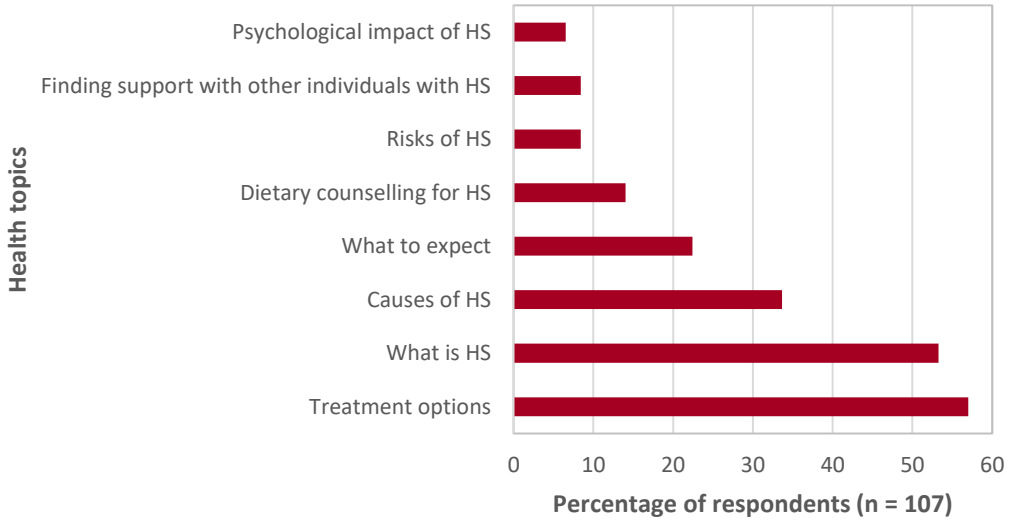
Based on responses from 82 respondents, the median number of missed days of school/work is 3, with a range of 1 to 29 days per month.

- For 91% (n=100/110) of respondents, HS has a negative effect on work/school
- For 97% (n=108/111) of respondents, HS has a negative effect on their personal life

Section V: Knowledge of HS

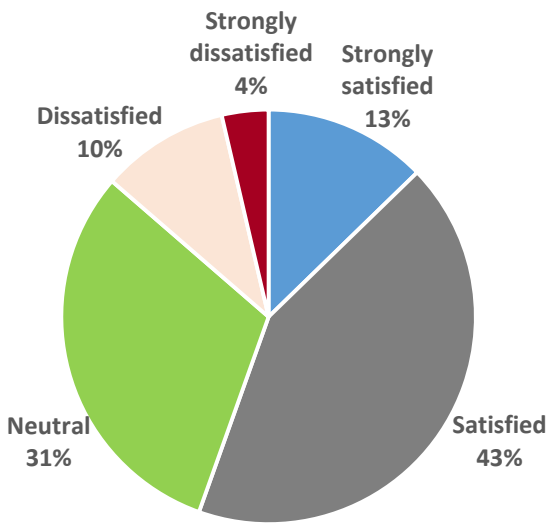
More than half of 107 respondents from Canada and the US remembered that HCPs had provided them with information about the basics of HS, including what this condition is, and treatment options (Figure 17). However, less than 10% of patients received counselling from their HCPs on two topics that are critical to their well-being and quality of life: the psychological impact of HS and how to find support with other individuals with HS.

Figure 17: Topics for which an HCP Provided Information to the Patient



The vast majority of respondents (86%) indicated that they were satisfied or neutral about their understanding of HS (Figure 18), suggesting that it is not a primary area of concern for them.

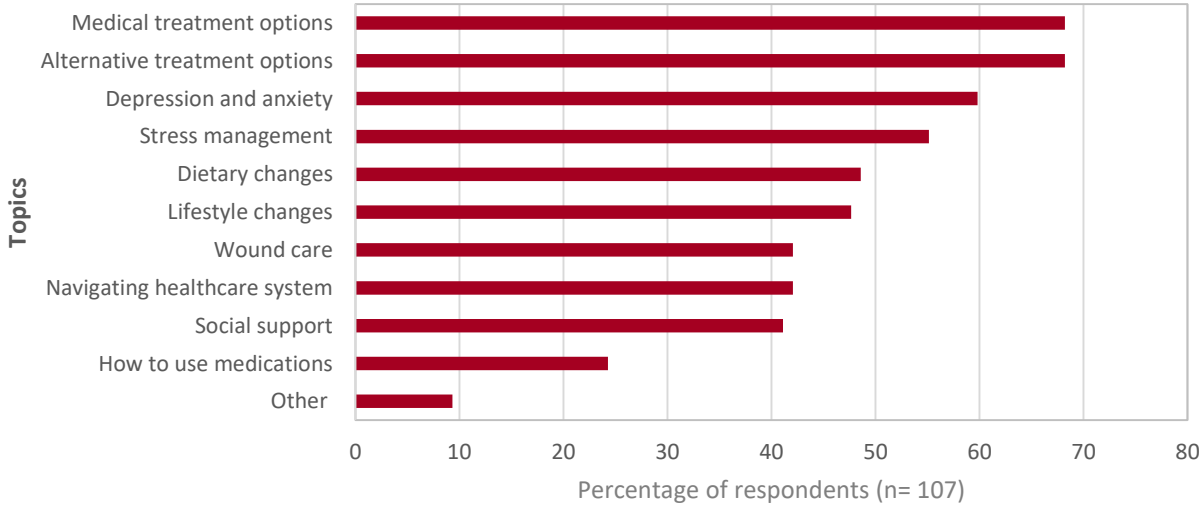
Figure 18: Satisfaction with Knowledge of HS



Section VI: HS-Related Patient Needs

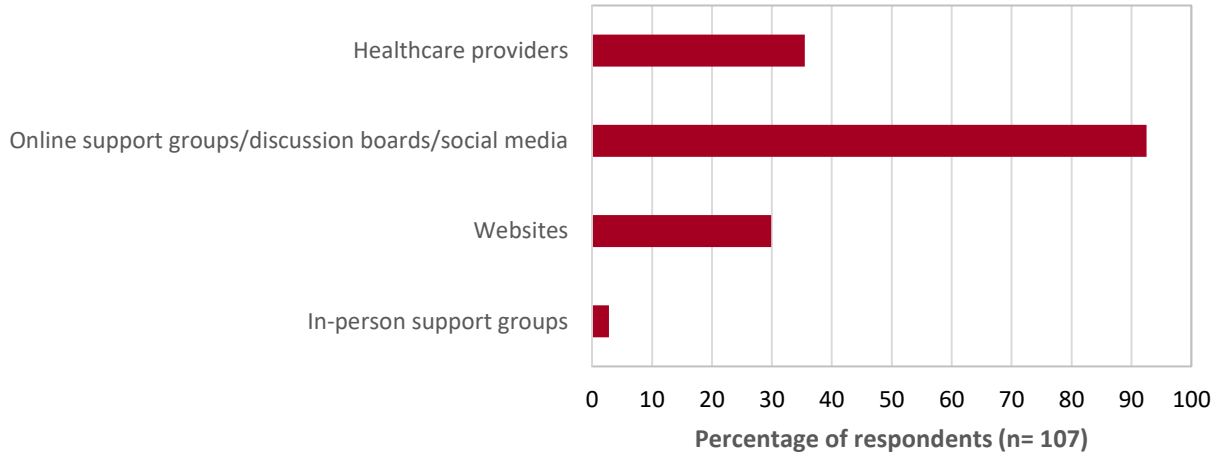
Although, there is clearly satisfaction with patients' own knowledge of HS, of 107 respondents, all indicated that they require support in multiple areas of HS symptom management (Figure 19). The most popular responses were around treatment options for symptoms that could be seen, and were likely interfering with daily life. However, over 50% indicated that they need assistance with managing the less visible impact of HS, specifically depression, anxiety and stress, further speaking to the debilitating nature of this disease.

Figure 19: Areas for which Patients with HS Need More Education



We asked where patients turn to gain information about HS (Figure 20). Of all respondents, 35% seek an HCP. However, online sources are in most cases much more readily accessible and immediate, and the vast majority (95.3%) consider these - be it social media, online health discussion boards or online support groups - as their primary means of HS information.

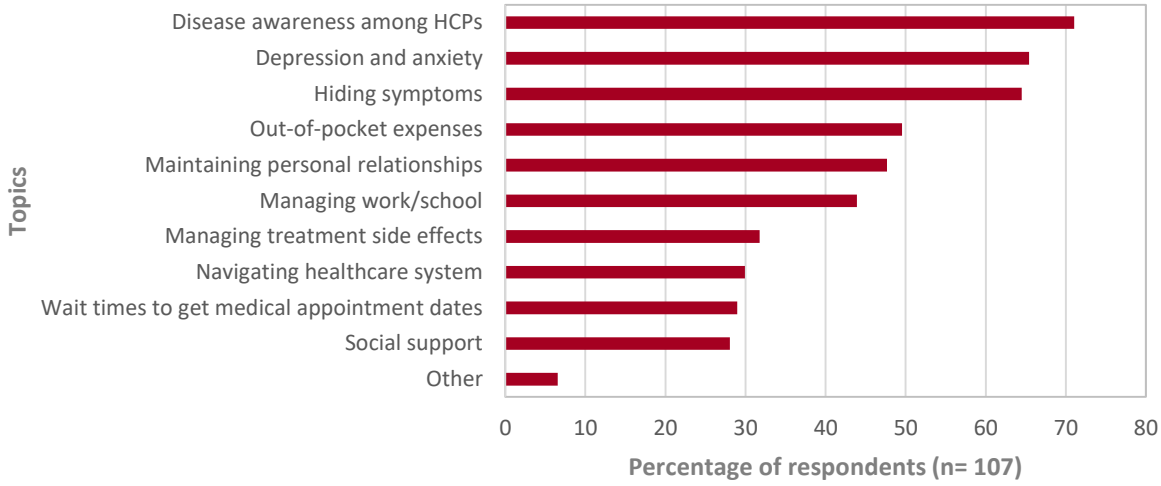
Figure 20: Patients' Primary Sources of Information on HS



Of the 107 respondents who completed the question, all revealed that they struggled with more than one aspect of having HS, and in the majority of cases, several topics (Figure 21). There was no topic listed than did not resonate with respondents, in terms of a challenging area. However, more than 60% of respondents indicated that a lack of disease awareness among HCPs, managing their depression and anxiety, and hiding the visible symptoms of HS in their work and personal lives were topics that they struggled with the most.

"Other sufferers are the best resources, not doctors."

Figure 21: Areas of Struggle for Patients with HS

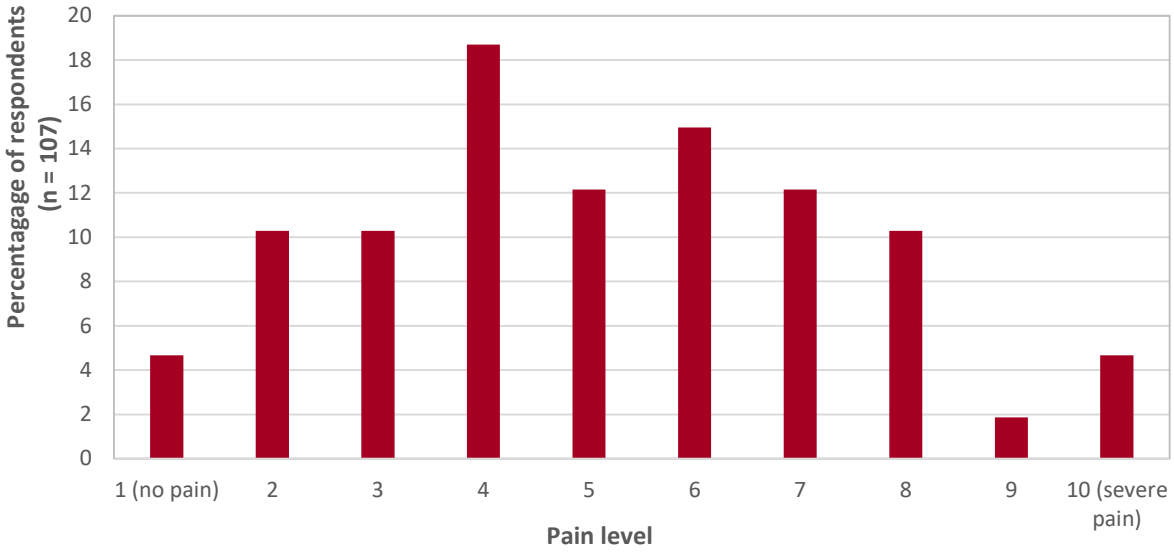


Section VII: Pain Management

"The immense pain is at times so harsh that I cannot move my body without crying in pain. I cannot work like this. It's a living nightmare that I pray will go away."

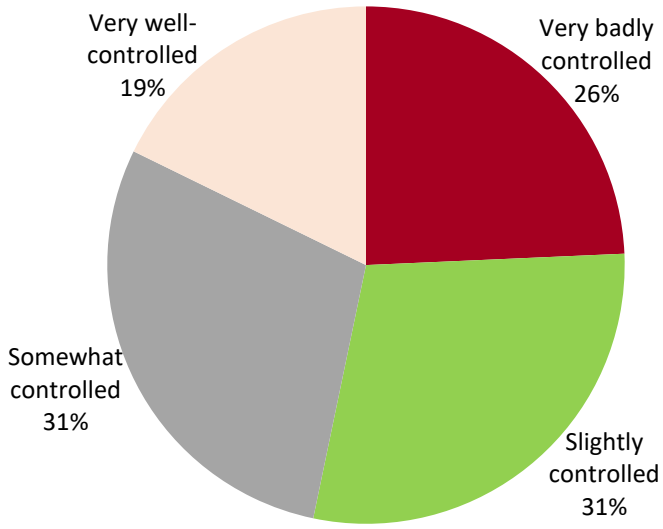
Pain management is considered to be one of the most important unmet needs of HS patients. Respondents were asked to indicate their level of pain on a typical day from 1 (no pain) to 10 (severe pain, Figure 22). Nearly all patients experienced some degree of pain daily, and on average, moderate pain (5 out of 10).

Figure 22: Pain Level on a Typical Day



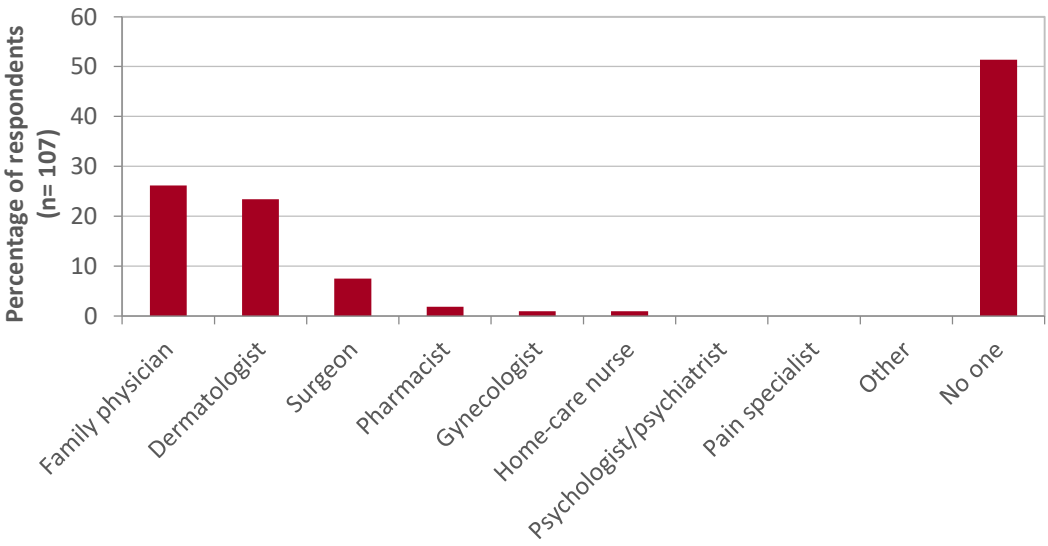
Most patients do not currently have a successful pain management regimen. Less than 20% of all respondents (n = 107) think that their pain is very well-controlled, and more than one-quarter consider their pain to be very badly controlled (Figure 23).

Figure 23: Pain Control on a Typical Day



While 49% of the 107 respondents have their pain managed by at least one HCP (primarily, family physician and/or dermatologist), the remainder indicated that they do not (Figure 24). They are therefore self-managing their pain with home treatments and over-the-counter medications, if at all. The fact that pain specialists are not part of the HCP team is a significant gap for individuals with HS.

Figure 24: HCPs that Help Patients with Pain Management



Recommendations

The results of the HSPE survey combined with Canadian healthcare utilization related to HS illuminate the difficult journey that patients must travel. The path to diagnosis is long, and often strewn with misdiagnoses, healthcare providers who are unfamiliar with HS and how to treat it, judgement from others about hygiene and self-care, and feelings of shame and embarrassment.

The impact of HS on a person's quality of life is significant and far-reaching. Symptoms including severe pain, seeping boils, odor and drainage, make work-life difficult, often placing restrictions on what individuals are able to do, including sitting for long periods of time, walking, lifting, and wearing a uniform. Beyond the physical effects, the ramifications of HS spill into personal lives as well, greatly affecting the ability to socialize comfortably with friends, family and co-workers. Those with HS are constantly plagued with feelings of fear, shame and dread, and become adept at avoiding situations that others take for granted.

Given their experiences, it is perhaps inevitable that those with HS are more likely to suffer from depression. Sixty-percent of our survey's respondents indicated that they require more information on depression and anxiety. Additionally, after "disease awareness among HCPs", the most common area of struggle was found to be depression and anxiety. This corroborates the results of a recent study of HS in the US, which found that over 40% of patients with HS had been diagnosed with depression.[7,8]

Although not asked specifically within the HSPE Survey, intimacy issues were described by several respondents, in their response to a question asking how HS affects personal lives. This has been highlighted in other studies which found that those who have HS have a high prevalence of sexual dysfunction.[9,10]

Our survey's results on work absenteeism also support previous studies. We found that individuals with HS miss an average of 3 days a month, similar to a Denmark study that observed a loss of 33.6 workdays/year.[11] The financial and emotional implications of this can be very detrimental on the well-being of those with HS, and many respondents commented on the job losses that they have endured because of their condition.

"Sometimes the pain is excruciating and I'm unable to work or engage in activities. The bumps and wounds often seep or ooze, causing embarrassing stains and ruining my clothing."

Despite the amount of time spent researching the condition, networking with other patients, and attempting various prescription and over-the-counter medications, as well as home treatments, our results indicate that this extensive experience with easily accessible therapies has yielded little success. Despite a tremendous

unmet need, only a small proportion have had access to newer therapies that show potential in symptom management.

Given the rising prevalence of HS, the impact of this disease on patients' well-being, and ability to function in society, and the significant healthcare utilization of these patients both before and after diagnosis, it is important to determine how provincial healthcare systems can better support these patients. We advocate for the following changes to patient care:

- Increase HS awareness for healthcare providers who are most likely to see a case. Time to diagnosis for future patients could be reduced by providing educational sessions and toolkits to dermatologists, family physicians and ER physicians, including information on i) common patient profiles for HS, ii) diseases for which HS is often misdiagnosed, and iii) treatment options.
- Evaluate every patient with HS for depression and offer support, care or referral to a specialist, if evident. A well-validated patient-reported outcome questionnaire for depression should be part of the baseline standard of care for recently diagnosed patients.
- Expedite funding decisions for new treatments of HS which have a strong benefit/risk profile. Individuals with HS have attempted numerous treatments and therapies to manage their debilitating symptoms. None have offered strong improvement to a significant proportion of patients. Access to new and promising treatment is critical to helping patients begin to regain their quality of life.
- Integrate a pain management discussion into every interaction with a patient with HS. Given the very visible symptoms of HS, it is easy to deprioritize other patient needs. 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.
- Develop a coordinated multi-disciplinary approach for managing HS among various healthcare providers to provide optimal care. Further research is needed to understand how to address the complex and varying needs of an individual with HS, define which healthcare provider types should be involved, and to tailor care accordingly.

We hope that this report will provide the foundation for further research in this area, and form the basis for the future tracking of progress towards the goals of optimizing the care of Canadians with HS.

Acknowledgements

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