

# Effectiveness & Patient Satisfaction with Treatment Options for HS in Canada: Results from the HS Patient Experience Survey

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## Learning Objective

To provide an overview of the patient experience for individuals with hidradenitis suppurativa (HS).

## Take Away Messages

1. Diagnoses are being made more quickly than previously reported in 2017 but are still taking too long
2. 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 their symptoms
3. Access to new and effective treatments is critical to improving health outcomes and quality of life for these patients



# Plain Language Summary

## ▪ **Why this study was needed**

A survey of patients with HS was conducted to determine gaps in patient care. Our aim was to describe the patient experience for individuals with HS, including path to diagnosis, symptom control, experience with treatments, healthcare utilization, and impact on quality of life.

## ▪ **What this study showed**

- A total of 537 surveys were received (73 from Canada).
- The average age was 38 years with a range of 14 to 73 years.
- Median time from symptom onset to HS diagnosis was 7 years for Canadian respondents.
- Pre-diagnosis, 97% of respondents visited a physician regarding symptoms, and 48% made 10 or more visits. More than half made at least one trip to the emergency room, and 16% visited 10 or more times.
- Of the Canadian respondents, 83% received at least 1 misdiagnosis, and an average of 3 misdiagnoses.
- 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.

## ▪ **Why this is important**

These results suggest that HS 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 their symptoms.

# Methods

## Development of the HS Patient Experience Survey

- In 2017, the Canadian Skin Patient Alliance (CSPA) collaborated with the Canadian HS Foundation and patient group HS Aware to develop an online survey titled the **Hidradenitis Suppurativa Patient Experience (HSPE) survey** as a quality improvement initiative for diagnosis and treatment of HS.
- In January 2020, the survey was updated with additional questions to more comprehensively examine all aspects of daily life that are affected.
- **Survey questions** included information on demographics, diagnosis, healthcare journey, disease related costs, disease impact, impact of behavior changes and treatments, disease knowledge, and pain control. The survey was created on the Survey Monkey website and was designed to be completed within 25 minutes. It was extensively reviewed and pilot-tested for clarity and comprehensiveness.

## Dissemination of the HS Patient Experience Survey

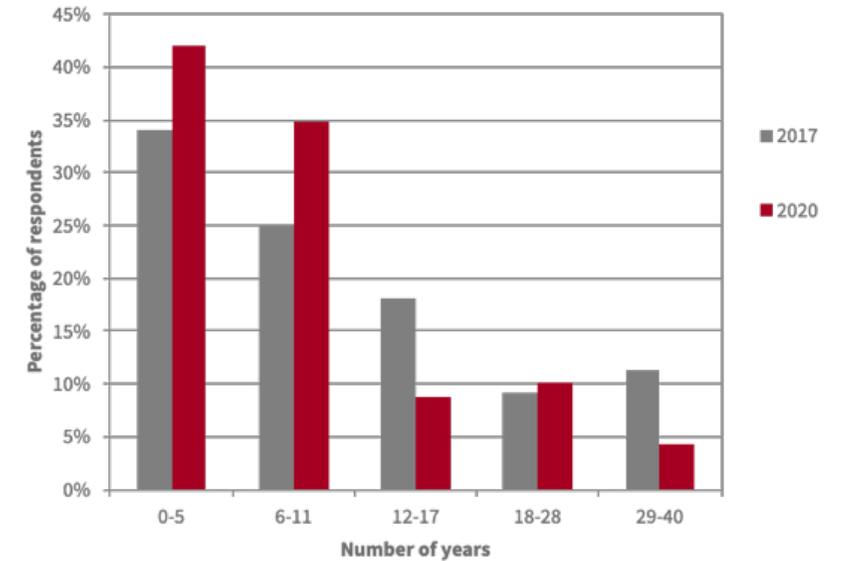
- In 2020, individuals with a formal diagnosis of HS or a self-diagnosis based on the presence of HS symptoms were invited to complete the survey. No geographical restrictions were applied, and the survey was distributed internationally.
- The survey link was disseminated through the CSPA's website and social media channels; the Canadian HS Foundation; social media channels of Patient Commando, an organization empowering patient choice; and local, national and international HS patient groups. The survey was open from January 6 to February 17, 2020.

# Respondents' Geographical Location

Country	Number of Survey Respondents
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, United Arab Emirates <sup>a</sup>	23
<b>Total</b>	<b>537</b>
<sup>a</sup> 1-3 respondents from each country	

# Seeking A Diagnosis

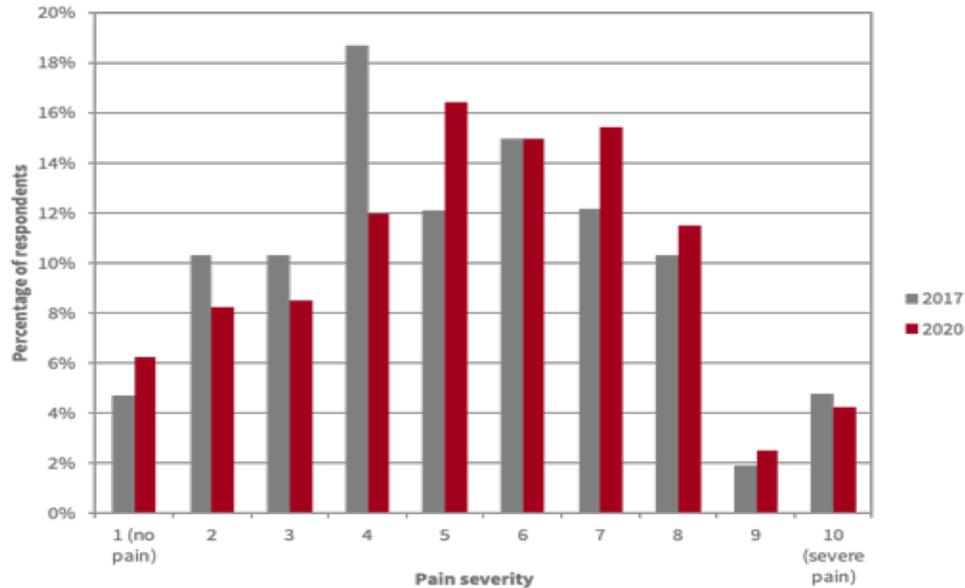
Number of years from symptom onset to HS diagnosis (n=69)



## Median Wait Times

Provider	2020 International	2020 Canada	2017 Canada
Dermatologist	84 days	167 days	180 days
Surgeon	56 days	180 days	150 days

# Pain



- Pain is a **debilitating** symptom of HS
- Only **11%** of all respondents consider their pain to be **very well-controlled**, down from 19% in 2017
- **46%** think their pain is **poorly controlled**

# Impacts on Daily Life

## Impacts on Family Life

- Impacts family activities, including parenting
- Impacts family finances
- Impacts mental and emotional health of whole family: worry, loss of hope, embarrassment

## Impacts on Work Life

- Inhibits career progression
- Impacts mental health
- Necessary to adopt coping strategies

*"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 worry about odor. I have had bandages come off and slide down my pant leg and I find them on the floor at the office."*

## Impacts on Social Life

- Inability to engage in social interactions
- Symptoms and side effects impact ability to be active
- Clothing options are restricted
- Impacts mental health and personal relationships

## Impacts on Intimacy

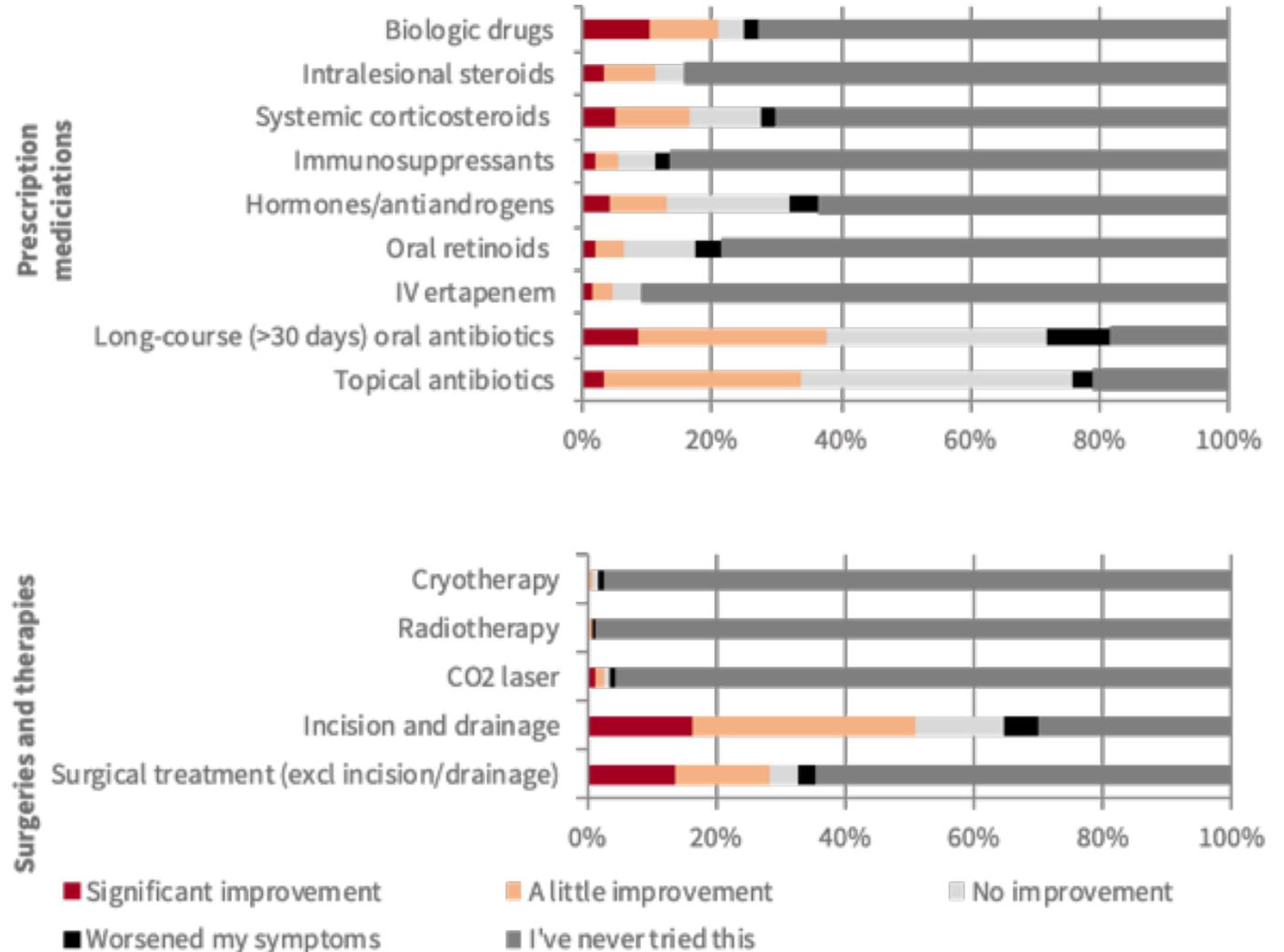
- Scarred by previous partner's reaction
- Fear and anxiety about being intimate
- Friction can lead to a flare
- In too much pain to be touched
- Weight gain from inability to exercise decreases confidence & self-esteem

# Treatments



- Patients tried an average of **15** treatments, surgeries & lifestyle modifications
- Of those who have tried these treatments:
  - 39% were helped by non-I&D surgery
  - 38% were helped by biologics

*“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... Antibiotics are not the answer unless there is actual infection, we need to find out 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.”*



# Conclusions

1. Diagnoses are being made more quickly than previously reported in 2017, but 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 their symptoms.
2. Individuals with HS have attempted numerous treatments to manage symptoms, with minimal improvement for most, underscoring that access to new and effective treatments is critical to improving health outcomes and quality of life for these patients.
3. The 11 health system recommendations identified in the report will help raise awareness, improve diagnosis, access to treatment and comprehensive care, and support patients living with HS.

## References:

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**Full report available:** <https://www.canadianskin.ca/advocacy/hs-report>

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