

SCARRED FOR LIFE: LIVING WITH HIDRADENITIS SUPPURATIVA (HS)

Hidradenitis suppurativa is a devastating condition affecting up to 4% of North Americans, and characterized by recurrent boils in the folds of skin, resulting in unpleasant odor and discharge.

SURVEY SAMPLE

167 surveys from individuals with HS





from Canada and United States





LONG DIAGNOSIS JOURNEY

of HS patients had more than 7 family physician visits before diagnosis



of HS patients had more than 10 medical emergency room visits before diagnosis

Average time for diagnosis: 9 years



Average age at diagnosis: 32 years

Average referral wait time for dermatologist: 180 days



MISDIAGNOSIS IS COMMON

8/10 individuals had at least 1 misdiagnosis for HS

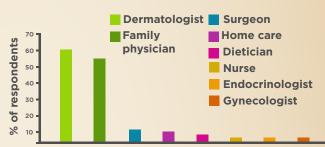


0 10 20 30 40 50 60 70 % of respondents

HS SUFFERERS ARE DISSATISFIED WITH PRE-DIAGNOSIS CARE



MAIN HS CARE PROVIDERS: FAMILY PHYSICIANS & DERMATOLOGISTS



HS IMPACTS QUALITY OF LIFE

Top 3 areas of struggle







91% HS negatively affects my work/school life



Less than 1/10 patients received counselling from their healthcare provider for HS



9/10 HS patients rely on online support groups for HS information



MOST HS TREATMENTS ARE MINIMALLY EFFECTIVE

20% said surgical treatment provided significant improvement of HS symptoms



18% said dietary and lifestyle regimens provided significant improvement of HS symptoms



Less than 30% have tried biologics, oral retinoids and corticosteroids for HS



LIVING WITH HS IS TIME-CONSUMING

Activity

average minutes per month



Attending medical appointments

65.5



Researching HS information

300



Wound care

300



Shopping for HS products

120



Participating in patient support groups

300



"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."

RECOMMENDATIONS



Increase HS awareness for healthcare providers.



Evaluate HS patients for depression and offer support.

Integrate a pain management discussion.



Develop a coordinated multi-disciplinary approach for managing HS.

Expedite funding decisions for new effective treatments of HS.



