A Guide to Hidradenitis Suppurativa: Living with HS

Editors
Leah A Johnston, Susan M Poelman

Associate Editors
Rochelle Tonkin, Elizabeth O'Brien,
Marc Bourcier, Raed Alhusayen

Canadian Hidradenitis Suppurativa Foundation, Richmond Hill, Ontario, Canada

To all patients living with HS.
“It is not the strength of the body that counts, but the strength of the spirit.”

- J.R.R. Tolkien

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Disclaimer

The information in this book may not apply to all patients, all clinical situations or all eventualities, and is not intended to be a substitute for the advice of a qualified physician or another health professional. Always consult a qualified physician about anything that affects your health, especially before starting an exercise program, changing your diet or using a complementary therapy not prescribed by your doctor.

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CHAPTER 1

Written by: Leah Johnston, Susan Poelman, Elizabeth O'Brien

Chapter Introduction

The goal of this book is to help individuals with hidradenitis suppurativa (HS) to learn more about HS and how to effectively manage this condition. This book is also designed for family members and friends of HS patients, as well as generalist healthcare practitioners who would like to increase their understanding of HS and the challenges associated with this condition.

Hidradenitis suppurativa is a chronic inflammatory skin disease which causes inflammatory lesions to develop in areas of the body which contain a high density of apocrine sweat glands. Common areas where HS develops includes the armpits, underneath the breasts, inner thighs, groin and buttocks. This condition has been linked to some genetic mutations, and it is important to understand that HS is not an infectious disease and it is not contagious.

It is important to know that HS is not an infection. It is not contagious.

This disease is estimated to impact about 1-4% of the general population, although it is commonly misdiagnosed, and the true prevalence may be higher than current statistics show.[1]

The average patient visits an average of five healthcare practitioners over an average of 8 years before receiving a diagnosis of HS.[1,2] HS can progress and become severe if it is not diagnosed and treated at an early stage of the disease, therefore raising awareness of HS in both the general population and with healthcare professionals is crucial. HS can also be associated with other medical conditions, so an understanding of these conditions and their symptoms can help HS patients to advocate for themselves at medical appointments.

Although there is currently no cure for HS, it can be managed through topical creams, oral medications, injectable medications, laser treatments, and surgical procedures. There are many ongoing clinical trials and new drugs being developed to treat HS, so there is hope that management of HS will continue to improve for patients.

In this book, we will discuss the risk factors for HS, what causes HS lesions to form, as well as signs and symptoms of HS. For readers who believe that they or someone they know may have HS, we will discuss the process of diagnosing HS and other medical conditions that are associated with HS. Treatment options and lifestyle

modifications that other people with HS have found to be helpful will also be discussed. Both HS patients and expert physicians were consulted in creating the content in this book. We hope that readers will find this resource to be a comprehensive guide that will make a new diagnosis of hidradenitis suppurativa feel less overwhelming and provide a framework for how to seek care and manage challenges that may arise with this condition.

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CHAPTER 2

Written by: Leah Johnston, Susan Poelman, Elizabeth O'Brien

What is HS?

Chapter Introduction

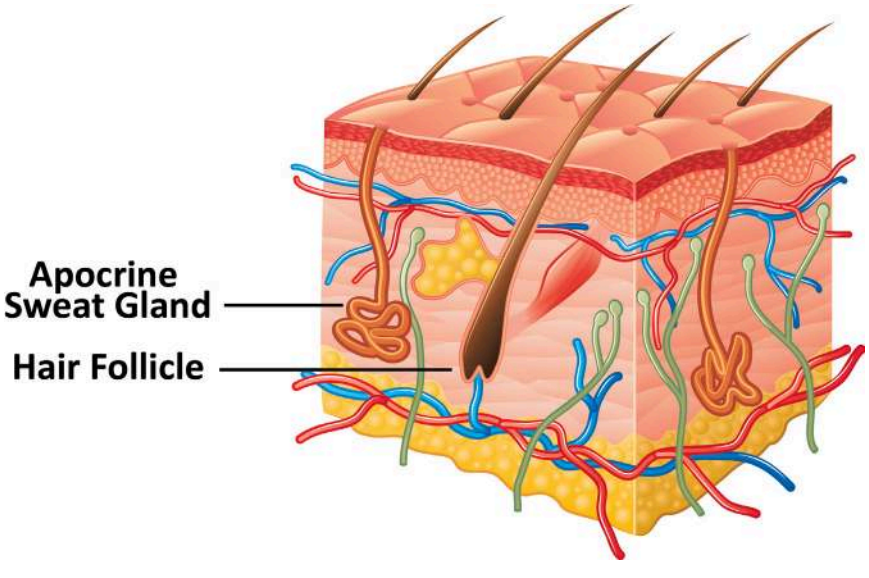
Although the exact cause of HS is not currently known, research so far suggests that a combination of genes, defects in the structure of hair follicles and sweat glands, immune system activation and hormones may play a role in the development of HS. With increasing knowledge and awareness of HS among physicians and researchers, there have been recent advances in the diagnosis and management of the condition. It is important to understand that HS is not an infectious disease and cannot be spread to others.

History of HS

HS was first described in the 1850's by a French surgeon named Aristide Verneuil, who was focused on wound care and treating abscesses. The disease was called Verneuil's disease for years and was observed as mainly developing in the skin folds of the body, where there are many sweat glands. The term "Hidraden" refers to sweat glands and the term "suppurativa" refers to producing pus.

The term "Hidraden" refers to sweat glands and the term "suppurativa" refers to producing pus.

Early understanding of the disease was that it was the result of an infection. The pus that develops in the glands was thought to be a sign of infection, which led to antibiotics being used to treat the condition. Almost by accident, it was discovered that certain antibiotics did provide relief for many patients with HS. But "usual" antibiotics – those used to treat skin infections — are not effective and should not be used for long periods of time. The antibiotics that helped HS patients were antibiotics that are known to have anti-inflammatory effects and are also used to treat acne.



How HS develops

HS is primarily a disease of the skin, and it is likely you will have a visit with a dermatologist if you have been diagnosed with HS. While there is still some uncertainty about the exact mechanism of how HS develops, it is currently thought to be a disease of the hair follicles in areas of the body that contain apocrine sweat glands. Body sites most affected include the underarms, chest, buttocks and groin.

The skin in areas of the body that contain apocrine sweat glands have numerous specialized hair follicle groups which are called pilosebaceous-apocrine units.[1] A pilosebaceous-apocrine unit contains a central hair follicle which is surrounded by apocrine sweat glands, oil-producing glands called sebaceous glands, skin cells (keratinocytes) and skin stem cells. Other sweat glands, called eccrine sweat glands, are also present in the surrounding skin. Hormone receptors surround the hair follicles and glands and can change the activity of the glands.

Some researchers are focusing on the hormonal component of HS (given it is a disease that is much more frequent in women than men) while others are focusing on the contribution of bacteria to the disease, and still others are concentrating on the immune system.

Genetic mutations as well as environmental factors such as hormones, smoking, sweating, and skin friction can lead to abnormalities in the structure of hair follicles as well as the functioning of the apocrine sweat glands.[1] These abnormalities cause build-up of dead skin cells, protein, sweat and other skin cell contents in hair follicles. This causes blockage of the hair follicle instead of normal breakdown and release of this content. Eventually, the build-up becomes large enough that it causes the hair follicle to dilate, rupture and release its contents into the local skin tissues. This causes activation of the local immune system of the skin, release of pro-inflammatory proteins and leads to the formation of inflammatory nodules and abscesses seen in HS.

Current treatments for HS, such as biologic medications, act to reduce inflammation by blocking the activity of inflammatory proteins that are released by immune cells.

Researchers have noted that HS usually develops after puberty and that HS rarely develops in children. This may be because the apocrine sweat glands are not fully developed at birth and androgen hormones start to be produced by the testicles in men and the ovaries in women at puberty.[1] Androgen hormones are known to have a stimulating effect on the apocrine sweat glands and in people who have a predisposition for developing HS, this can increase follicular occlusion and rupture. Medications that block the activity of androgens both throughout the body and more locally at the level of the hair follicle are commonly used to treat HS, especially if bloodwork has shown abnormally high levels of androgen hormones, especially in women.

It is important to understand that HS is not caused by an infection and it is not a contagious

or a sexually transmitted disease. Wound cultures of HS lesions typically grow only bacteria that are normally present on the surface of the skin. Although HS lesions are at risk of becoming infected in serious cases, these infections occur after years of having untreated wounds that do not heal properly and are a complication of having HS, not the cause.

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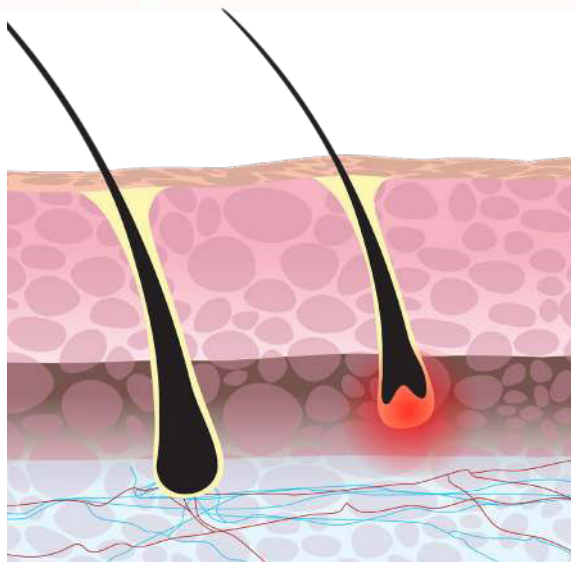

Prognosis

HS behaves differently in every individual patient. It does not have one linear, predictable pathway. In some patients, it starts as a mild disease and progresses to severe. In some patients, it always remains mild and in others, it commences with severe disease. About 68% of HS patients have mild disease, 28% have moderate disease and 4% have severe HS.[1] There are patients in whom HS goes into remission for good while other patients have ongoing flares and HS remains a chronic disease for them. There are no blood tests or other investigations that doctors can order that will predict whether or not HS will stay mild or progress to severe disease. With a clear understanding of the cause or causes of HS, more effective treatments will likely become available and improve outcomes for HS patients.

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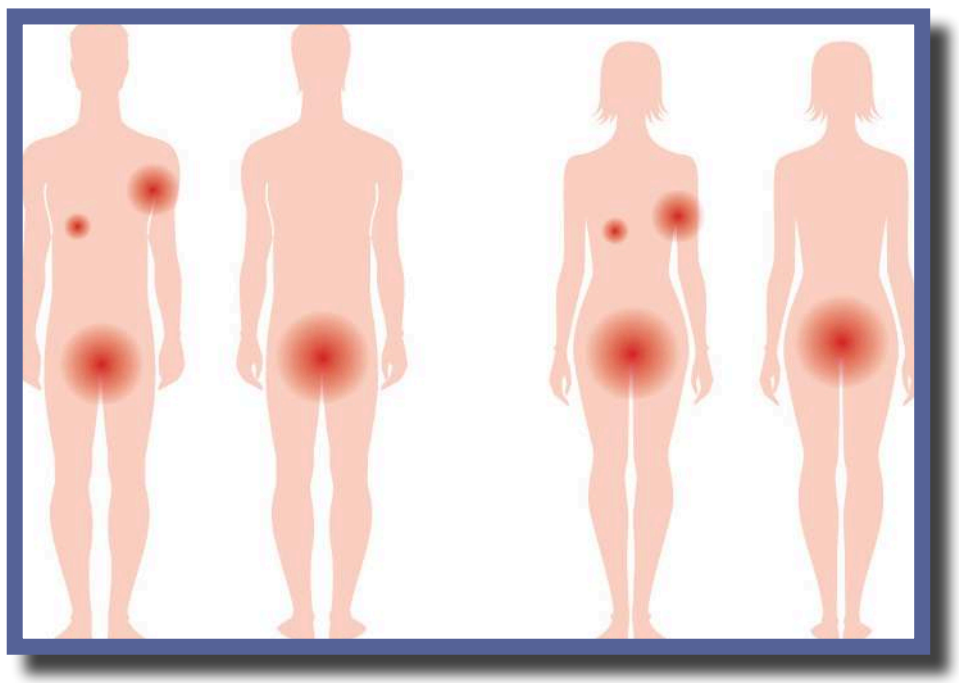


Challenges that HS Patients Experience

HS nodules and abscesses can be very painful when they arise. Because of the areas of the body affected, such as the underarms and inner thighs/groin, it can be very difficult for some individuals with HS to go about their daily activities such as sitting at a desk, walking, and lifting objects when they have a flare-up of their HS. Another concern is that HS nodules can be filled with pus and lead to an abscess, which can drain and have a foul smell. The pus can leak and also stain clothing. At more severe stages of HS, sinus tracts or inter-connected tunnels develop under the skin and this can be a source of chronic pain and drainage. Sinus tracts and significant scarring can even impact range of motion in the limbs. Many HS patients may feel self-conscious of the appearance of their HS. HS lesions often appear red and purple in colour and these lesions can leave discoloured scars on the surface of the skin as they heal. Some people with HS may avoid wearing certain clothes or doing activities that would make their HS lesions visible to others. Given the potential negative impact of HS on one's overall quality of life, early treatment and having an effective management plan for flare-ups is essential.

CHAPTER 3

Written by: Leah Johnston, Susan Poelman, Marc Bourcier

Patient Demographics and Risk Factors for HS

Chapter Introduction

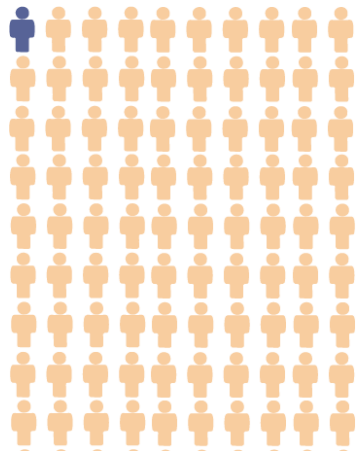
There is no one patient that represents the “typical” HS patient. HS can impact people of diverse ages, gender identities, races, and socioeconomic backgrounds. However, there are some risk factors for HS that have been identified in past research, such as young age (onset in late teens to late 20’s is most common), having a family history of HS, female sex, some ethnic backgrounds, low socioeconomic status, having other inflammatory medical conditions, a history of smoking, and being overweight or obese.[1]

The severity and disease course with HS can also be highly variable, with some patients who will have a mild disease course with intermittent periods of disease flare-ups, while others may experience a more progressive and severe course of the disease.

Prevalence of HS

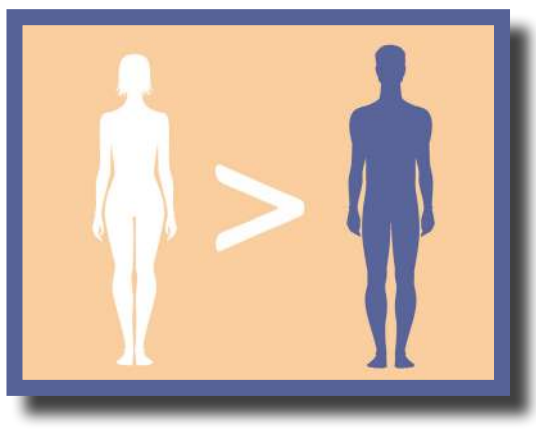
Hidradenitis suppurativa was previously classified as a rare disease. However, new evidence is emerging that the prevalence of HS may be up to 1-4% of the general population.[2] The average time from a patient to get diagnosed after disease onset is 8 years and statistics show that patients often seek care from 5 different physicians before being diagnosed with HS.[2] High rates of misdiagnosis may lead to the prevalence of HS being falsely low.

There are multiple reasons why HS may have been previously underdiagnosed. One issue is that HS has not been included in medical school core dermatology curriculum at many medical schools across North America. In addition, not all universities have a mandatory dermatology rotation in the clinical medical school years or in the residency training programs for specialties such as family medicine and emergency medicine, and these physicians are often the first point of contact with the healthcare system for HS patients. Another challenge for practitioners without specialized training in dermatology is that HS can initially appear similarly to bacterial skin infections, acne, ingrown hairs, sexually transmitted infections, or other inflammatory diseases such as perianal Crohn's disease. As awareness of HS increases among both healthcare practitioners and patients, the true prevalence of HS may be higher than in previous reports.



It is interesting to note that pediatricians remark that in today's world many children are entering puberty at a younger age compared to previous generations. They note, for example, that they see children in their offices with acne who are 10 years old and younger.

Another barrier to HS diagnosis is that since HS typically presents in areas of the body that are covered by clothing, some patients have reported feeling uncomfortable or embarrassed about their symptoms and for this reason, they avoid seeking medical attention for their HS. Without proper awareness and education about what causes HS, HS may be falsely attributed to an issue of hygiene. The hope that dermatologists have for HS is that by increasing awareness of HS in the general population, patients will feel more comfortable seeking care for their condition and more patients will be diagnosed and treated at an early stage of the disease, which can help to halt progression and prevent long-term complications.



Risk Factors for HS

Age	HS most commonly starts in the teens and 20's, with an average age of onset between 20 and 24 years, but can also develop later in life.[1,3,4]
Family History	Up to 30-40% of patients with HS have a family history of HS.5 Specific gene mutations which affect a protein in the notch signaling pathway, called 'gamma secretase,' and mutations in genes such as PSTPIP1 have been associated with the condition, especially in cases where there is a family history of HS.1,6 Research on the genetic factors that contribute to HS is ongoing, so there may be more genes that are not currently known that can make someone more susceptible to HS.
Biological sex	People who have a female biological sex are more likely to be affected than males. Current statistics show a 3:1 ratio of females to males that are affected by HS.[5]
Hormones (excess androgens)	Polycystic ovarian syndrome (PCOS), which commonly presents with abnormally high levels of androgens, occurs more commonly in women with HS than women who don't have HS.[1] PCOS is discussed in Chapter 5. HS occurs after the onset of puberty in the majority of cases, which is when the apocrine sweat glands are fully developed and have receptors for activation by hormones. Increased levels of androgen hormones are produced by the testicles in men and the ovaries in women at puberty. Cases of new onset HS have been reported in transgender males after initiation of testosterone therapy, further implicating hormones as a contributing factor for developing HS.[7] Many women find that their HS is more likely to flare-up around the time of menstruation, so fluctuating levels of hormones may play a role.[8] Hormonal contraception use has been found to play a protective role against developing HS, which explains why certain types of oral contraceptives are prescribed to women to treat HS.[9] There are some reports of progesterone-only methods of birth control contributing to worsening of HS.[10]

Race	HS is more common in people of African and Caucasian descent.[11] However, HS can occur in people of all races and ethnic backgrounds.
Smoking	Statistics show that 70-75% of HS patients currently smoke and 10-15% have a past history of smoking.[1]
Obesity	Statistics show that HS occurs more frequently in people who are overweight or obese.[1] Experts believe that this is likely due to increased friction and sweating in areas of the body where HS occurs, as well as an increased number of skin folds. However, HS also occur in people who are underweight or have a normal range BMI.
Other inflammatory conditions	HS is more common in people who have other inflammatory conditions, such as inflammatory bowel disease, acne, diabetes, inflammatory arthritis, and metabolic syndrome.[1] These conditions are discussed in detail in Chapter 5.
Medications	Lithium, progesterone-only contraceptives and hormonal IUDs[10,12]

Research shows that anywhere from 40% to 92% of patients with HS are smokers.

Because HS affects women with much more frequency than it affects men, doctors are studying the role of hormones in the development of the disease.

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CHAPTER 4

Written by: Leah Johnston, Susan Poelman, Marc Bourcier

HS Signs, Symptoms and Diagnosis

Chapter Introduction

Many conditions in dermatology can be confused for other conditions because symptoms, such as a rash, are not specific to one condition. One of the most common features of HS are nodules occurring in specific locations. HS can sometimes be mistaken for a folliculitis or a bacterial furunculosis, which is a deep infection of hair follicles that can appear similarly to HS with nodule and abscess formation in similar locations.[1] However, HS is not caused by an infection and tends to recur, while bacterial furunculosis tends to go away and not recur after antibiotic treatment.

HS can be easy to diagnose for doctors who are familiar with it. However, healthcare professionals on the front lines, working in community clinics or emergency centers, for example, may not be able to make a diagnosis of HS and may have to refer a patient with suspected HS to a dermatologist. This chapter will discuss common signs and symptoms of HS so that patients and healthcare providers are aware of how HS presents. Systems for classifying HS based on severity will also be included in this chapter.

HS Terminology	Descriptions
Nodule	A raised, round lesion on the skin less than 10mm
Abscess or boil	A collection of pus on the skin presenting as a soft, raised lesion >10mm
Comedone	A collection of keratin on the skin surface with an opening
Sinus tract/tunnel	A tunnelling from the skin to a deeper area with fluid in the tracks
Pustule	A collection of pus on the skin surface < 10mm
Scar	A fibrosis of the skin due to previous lesions. Patients with HS commonly have a cord-like scar
Ulcer	Opening of the skin surface with loss of epidermis and dermis
Erosion	Opening of the skin surface with loss of epidermis only

Signs and Symptoms of HS

Physicians diagnose HS based on 3 main criteria: characteristic distribution of lesions, appearance of lesions, and a history of recurrence.[1]

1) Distribution (where the lesions occur on your body): HS most commonly occurs in the armpits, below the breasts, in the groin/inner thighs, and gluteal region. It is also possible for lesions to occur in less common areas, such as the neck, abdomen and behind the ears.

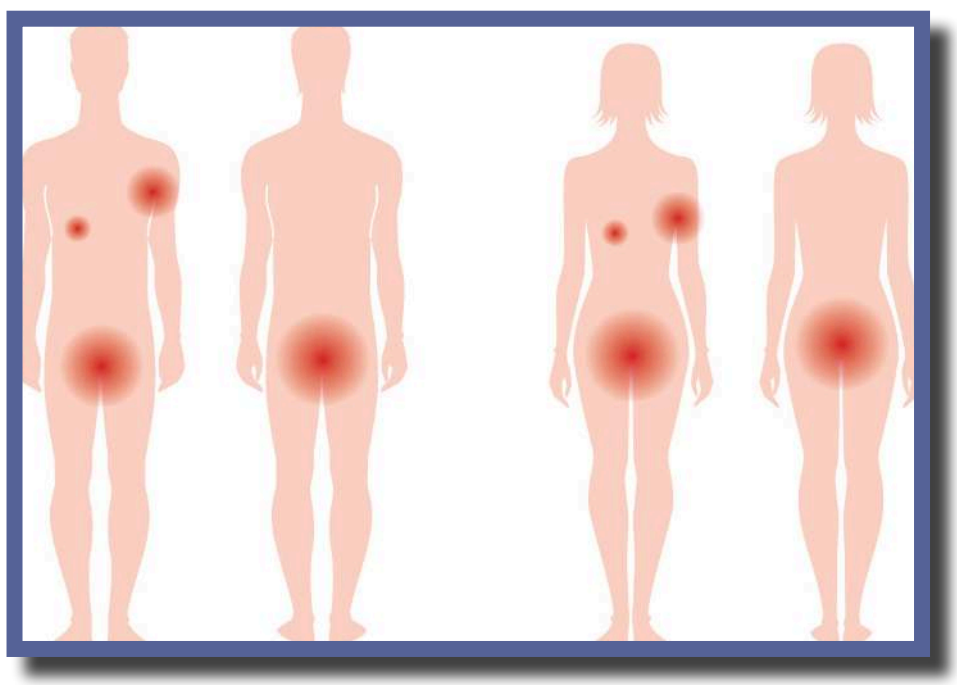
2) Characteristic lesions and symptoms: HS lesions can look like blackheads, small pimples or can be larger nodules or boils. These boils may rupture and leak fluid, pus or blood. Scarring can also appear as a result of previous HS lesions. Sinus tracts, which are tunnels that form underneath the surface of the skin and connect different HS lesions, may be present in more advanced stages of HS.

3) Recurrence: if you've had at least two boils in the past 6 months, it is very likely that you have HS. You may also have lesions that heal and then recur in the same spot on your skin.

Stages of HS

The Hurley staging system is the most commonly used scale to classify the severity of HS. There are 3 Hurley stages, with stage I referring to mild disease and stage III being the most severe stage of HS. Scarring and sinus tracts are generally associated with stage II or III HS. Not all patients move from Stage I to II and then III, but once HS progresses to a more advanced stage, it can be difficult to reverse some of the changes that have occurred in the skin, such as the formation of scars and sinus tracts.

The presence of either single or multiple nodules or abscesses without scars and sinus tracts would be considered Stage I, and Stage II would indicate the presence of scars or sinus tracts in addition to single or multiple nodules or abscesses. The most advanced stage or Stage III appears as many lesions on several areas diffuse



involvement of one or more areas of the body with the presence of multiple interconnected sinus tracts or tunnels. Stage I of the disease is the most commonly seen stage. Stage II is less common, and Stage III is the least commonly occurring. There are many scoring systems available to measure the severity of HS and response to treatment in patients with HS, and that's how your dermatologist keeps track of your disease process.

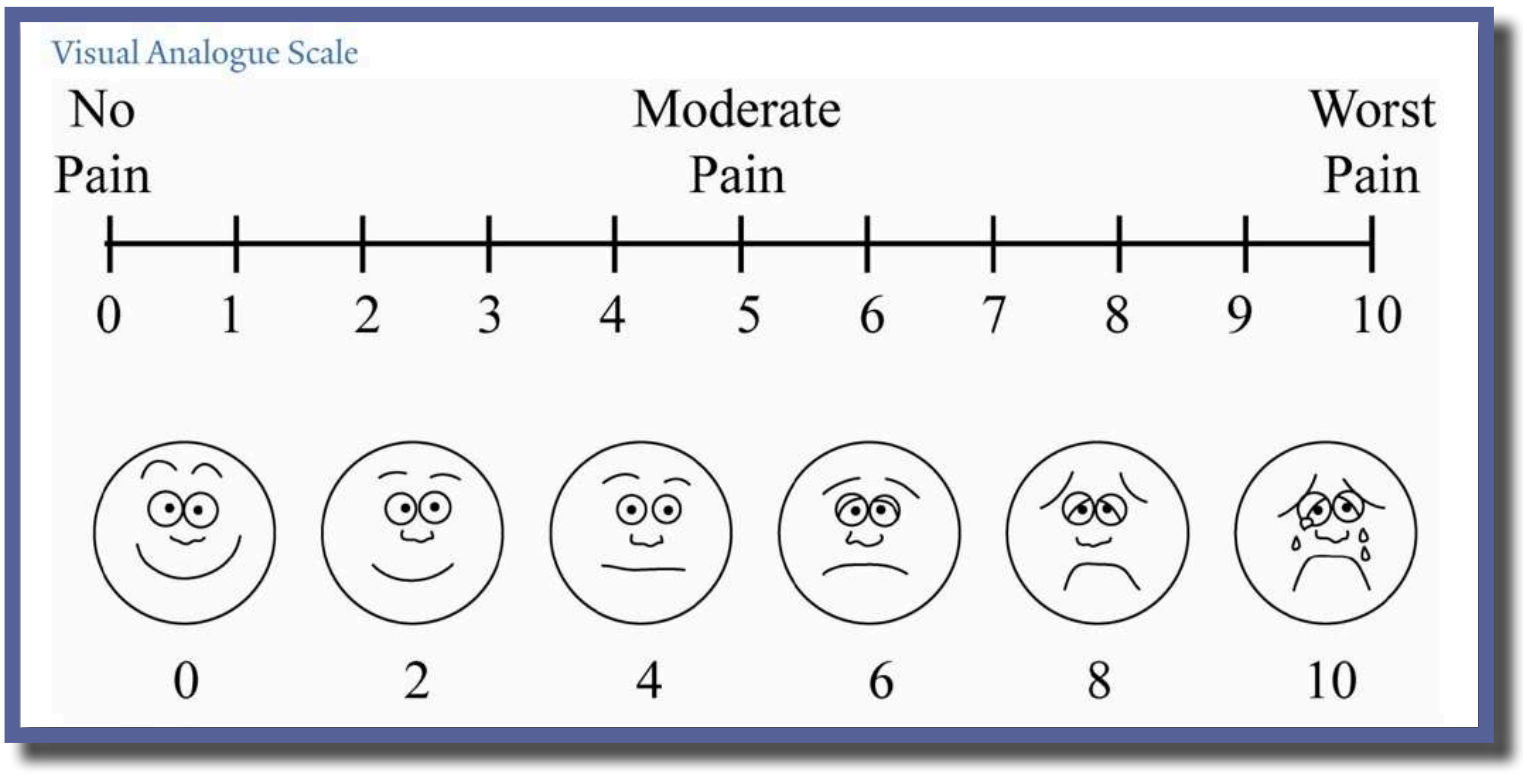
Stages of HS

Stage I
Abscess formation, single or multiple, without sinus tracts and cicatrization

Stage II
Recurrent abscesses with tract formation and cicatrization, single or multiple, and widely seperated lesions

Stage III
Diffuse or near-diffuse involvement or multiple interconnected tracts and abscesses across the entire area

Other common assessments that physicians use to assess the severity of HS are the Visual Analog Scale (VAS) for pain and the Dermatology Life Quality Index (DLQI). The VAS is used to measure both the overall pain you experience from having HS and the pain in the worst HS lesion. It allows patients to rate their level of pain from 0 to 10, with 0 corresponding to no pain and 10 indicating the worst possible level of pain. Scores of 1-3 indicate mild pain, which likely has a minimal impact on activities of daily living (ADLs), while 4-6 indicates moderate impact on ADLs and 7-10 indicates that pain has a major impact on your ability to complete ADLs.[2] The VAS can give your dermatologist a better idea of how pain from your HS may impact your daily life and help them to create a plan to manage your pain. Pain management is discussed in Chapter 9.



https://assessment-module.yale.edu/im-palliative/visual-analogue-scale

The Dermatology Life Quality Index (DLQI) is commonly used in dermatology to assess the impact of a skin disease on a patient's overall quality of life and their daily activities. The DLQI has been used to measure the impact of other conditions like psoriasis, acne, and eczema on a patient's quality of life. The DLQI contains 10 questions, which ask about how much the skin has impacted a patient's life over the course of a week. The answers range from 'very much' to 'not at all.' The DLQI also takes into account symptoms that HS patients may experience, such as pain or itch. The DLQI is used in more than 80 countries and available in more than 90 languages.

The DLQI scores range from 0 to 30, 30 being the more severely affected. The higher the score that you get on the DLQI, the greater the negative effect that the disease has on your life. **Some studies have shown that HS has a more profound negative impact on a patient's quality of life than do other conditions that affect the skin such as acne, psoriasis, and eczema.**

Dermatology Life Quality Index

Hospital No: Date: **DLQI**

Name: Score:

Address: Diagnosis:

The aim of this questioinnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick one box for each question.

1. Over the last week, how itchy, sore, painful or stinging has your skin been?

   Very Much ☐ A lot ☐ A little ☐ Not at all ☐

2. Over the last week, how embarrassed or self conscious have you been because of your skin?

   Very Much ☐ A lot ☐ A little ☐ Not at all ☐

3. Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?

   Very Much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐

4. Over the last week, how much has your skin influenced the clothes you wear?

   Very Much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐

5. Over the last week, how much has your skin affected any social or leisure activities?

   Very Much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐

6. Over the last week, how much has your skin made it difficult for you to do any sport?

   Very Much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐

7. Over the last week, has your skin prevented you from working or studying?

   Yes ☐ No ☐ Not relevant ☐

   If "No", over the last week how much has your skin been a problem at work or studying?

   A lot ☐ A little ☐ Not at all ☐

8. Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?

   Very Much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐

9. Over the last week, how much has your skin caused any sexual difficulties?

   Very Much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐

10. Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?

    Very Much ☐ A lot ☐ A little ☐ Not at all ☐ Not relevant ☐

Please check you have answered EVERY question. Thank You.

Adapted from AY Finlay, GK Khan, April 1992

Number	DLQI Severity
0 - 1	No effect on Patient's Lives
2 - 5	Small effect on Patient's Lives
6 - 10	Moderate effect on Patient's Lives
11 - 20	Very large effect on Patient's Lives
21 - 30	Extremely large effect on Patient's Lives

How to Find Support for Managing HS

If you think you may have HS, researching your condition is a great step in managing your health and will help you advocate for yourself when seeking care for your condition. The first step towards getting treatment for your HS is often to visit your family physician. In many Canadian provinces, you cannot book an appointment with a dermatologist directly and it is mandatory to be referred to a dermatologist by your family physician. Not all generalist physicians may be aware of HS, so it is important to be prepared to explain this condition if your provider is not familiar with it and how your symptoms may be consistent with HS.

Even if your primary care physician is knowledgeable about HS, it is often a good idea to see a dermatologist, as dermatologists can provide access to specialized treatments and services for HS patients that are not routinely offered at primary healthcare clinics. These treatments include biologic medications, laser hair removal, outpatient procedures such as deroofing surgery, and HS-specific community support resources. Certain topical creams, such as resorcinol, can only be found at compounding pharmacies that are associated with dermatology clinics. Medical treatments for HS will be discussed in Chapter 7.

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2. Visual Analog Scale. IM: Palliative Care. Yale University. Accessed August 31st, 2021. https://assessment-module.yale.edu/im-palliative/visual-analogue-scale

CHAPTER 5

Written by: Leah Johnston, Susan Poelman, Marc Bourcier

Other Conditions that are Associated with HS

Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) is a term used to describe conditions that are caused by an abnormal reaction of the body's immune system against tissues in the digestive tract.[1] This can lead to significant inflammation and if left untreated, can cause abdominal pain, persistent diarrhea, intestinal bleeding, and malnutrition, as nutrient absorption from the intestines is reduced. Inflammatory bowel disease is an umbrella term and the two main types of IBD are Crohn's disease and ulcerative colitis. Similar to HS, people who develop IBD often have a family history, as there are some genes that can pre-dispose people to developing IBD. Both Crohn's disease and ulcerative colitis have been associated with HS.

There are many similarities that have been found between HS and IBD.[1] There are specific genes that have been found to be associated with both IBD and HS. In addition, multiple inflammatory proteins have been identified that contribute to inflammation in both conditions. Tumor necrosis factor alpha (TNF-α) is an inflammatory protein that is targeted by multiple biologic medications that block its activity. TNF-α inhibitors, such as Humira and Remicade have been used successfully to treat both IBD and HS. Other inflammatory proteins that are associated with both IBD and HS include IL-1, IL-6, IL-17, and IL-23.[1] Studies are ongoing for medications that can help reduce the actions of these other proteins in HS.

Research has demonstrated that people with HS are 2 times more likely to develop Crohn's disease and are 1.[5] times more likely to develop ulcerative colitis than people without HS.[1] Overall, about 2-3% of HS patients also have IBD.[1] If you are having symptoms of IBD that persist for more than a few weeks, you should visit your physician for further testing to see if you could have IBD. Your physician may want to refer you to a gastroenterologist for assessment. A colonoscopy is typically needed to diagnose IBD.

1. Chen W, Chi C. Association of Hidradenitis Suppurativa With Inflammatory Bowel Disease: A Systematic Review and Meta-analysis. JAMA Dermatol. 2019;155(9):1022–1027. doi:10.1001/jamadermatol.2019.0891

PCOS

Polycystic ovarian syndrome is a hormonal condition that impacts women in their reproductive years. PCOS is characterized by excess production of androgens, which are also commonly referred to as 'male hormones.'[1] PCOS often presents clinically with irregular or absent menstrual cycles, hair loss from the scalp, unwanted body hair growth, acne, weight gain or difficulty losing weight, findings of multiple cysts on imaging of the ovaries, infertility, insulin resistance, and inflammation. This condition is often genetic and can impact up to 10-20% of women. Many women with PCOS are not aware that they have this condition and may not undergo screening for PCOS until they are having difficulty becoming pregnant. One study has shown that about 9.0% of patients with HS also have been diagnosed with PCOS, compared to 2.9% of the general population having PCOS.[1] Theories about why women with PCOS are more likely to have HS include excess androgen activity at hair follicles and increased systemic inflammation.

If you are a female patient with HS and have other symptoms of PCOS, your doctor may order blood tests to see if you could have this condition. These tests include FSH and LH, which are hormones from the pituitary gland which regulate the activity of the ovary, as well as tests for elevated androgen hormones, including DHEA-S, free testosterone and total testosterone.[1] In some cases, an ultrasound may be done to look for cysts on the ovaries, though not all women with PCOS have ovarian cysts and the presence of these cysts is not required to be diagnosed with PCOS. Your doctor may also order tests such as fasting blood glucose and a lipid panel to test for signs of insulin resistance and metabolic disease, which are more common with PCOS. If you have been diagnosed with PCOS, this is helpful for your dermatologist to know, as there is overlap between medications used to treat both HS and PCOS. These medications include select oral birth control pills, anti-androgen medications, and medications to help improve insulin resistance.

1. Garg A, Neuren E, Strunk A. Hidradenitis Suppurativa Is Associated with Polycystic Ovary Syndrome: A Population-Based Analysis in the United States. J Invest Dermatol. 2018;138(6):1288-1292. doi:10.1016/j.jid.2018.01.009

Anemia

HS has been associated with multiple different types of anemia, which is a condition of low levels of red blood cells. Symptoms of anemia include fatigue, pale skin, shortness of breath, dizziness and headaches.

Types of anemia that have been associated with HS include iron-deficiency anemia and anemia of chronic disease.[1] Physicians often order a Complete Blood Cell count (CBC) as part of routine bloodwork and this includes measurements of hemoglobin, a molecule in red blood cells and other measures of the body's iron stores. Particular tests such as total iron binding capacity (TIBC) and ferritin are often ordered on bloodwork to help your doctor differentiate between iron deficiency anemia and anemia of chronic disease. This is important as it will help to determine which type of anemia you have. Iron deficiency anemia can be improved by changing your diet and taking oral iron supplements. Anemia of chronic disease is not caused by having low iron levels and taking an iron supplement will not improve your condition. Anemia of chronic disease is associated with inflammatory conditions and first steps to treat this condition include treating the underlying inflammatory or autoimmune conditions that you have, as well as using medications that increase the body's red blood cell production in some cases.

1. Mondana Ghias, Sophie Cameron, Fiona Shaw, Yssra Soliman, Allison Kutner, Mark Chaitowitz, Steven Cohen, Morayma Reyes Gil, Anemia in Hidradenitis Suppurativa, Hepcidin as a Diagnostic Tool, American Journal of Clinical Pathology, Volume 152, Issue Supplement_1, October 2019, Page S15, https://doi.org/10.1093/ajcp/aqz112.029

Thyroid Disease

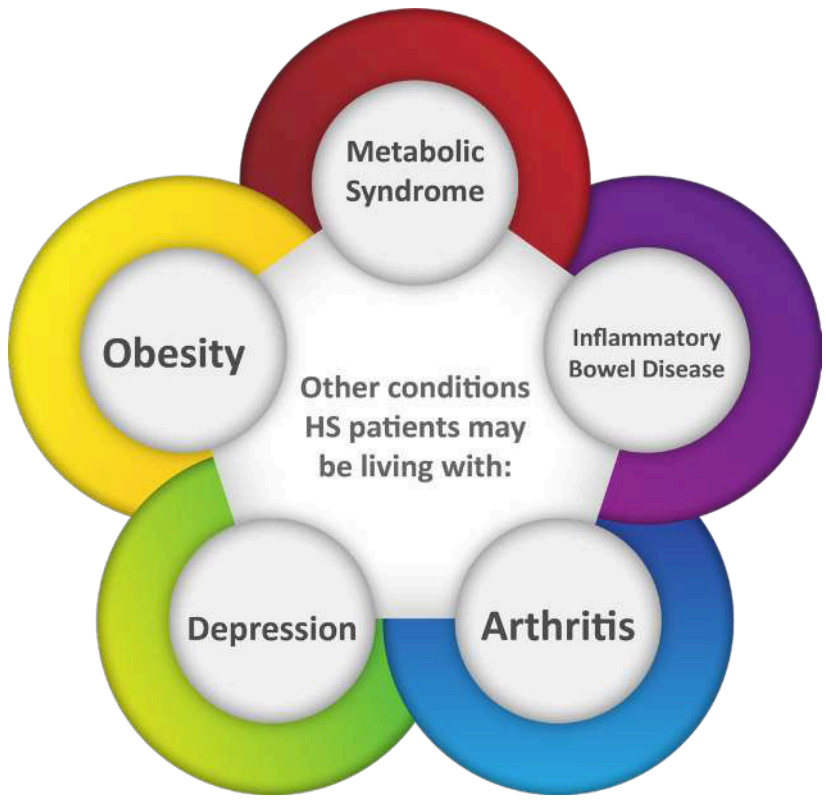
The thyroid gland produces hormones that are important for regulating metabolism and how different cells in the body use energy. Thyroid diseases are often caused by an autoimmune reaction of the immune system against the body's own cells or cell receptors. Two of the most common forms of thyroid disease are hypothyroidism, which is underactivity of the thyroid gland and low production of thyroid hormones, and hyperthyroidism, which is excessively high activity of the thyroid gland and production of thyroid hormones. There are medications that can be taken to help correct both types of thyroid hormone imbalances.

Studies have shown that people who have HS may be at an increased risk for both types of thyroid disease.[1] Thyroid disease can be screened for using routine bloodwork tests for a hormone called thyroid stimulating hormone (TSH). Your physician may choose to add this test to routine bloodwork every year or every few years to monitor your thyroid function.

1. Phan K, Huo YR, Charlton O, Smith SD. Hidradenitis Suppurativa and Thyroid Disease: Systematic Review and Meta-Analysis. J Cutan Med Surg. 2020;24(1):23-27. doi:10.1177/1203475419874411

Obesity

Research has shown that obesity may be a risk factor and may increase the severity of HS. Body mass index (BMI) has traditionally been used by physicians and researchers to classify weight into categories such as 'underweight,' 'normal weight,' 'overweight,' and 'obese.' BMI is calculated by taking one's mass in kilograms and dividing it by the square of the number of centimeters in the person's height. Being overweight is defined as having a BMI of ≥ 25.0 and being obese involves having a BMI of ≥ 30.0.



Some concerns with BMI as a measure of obesity is that it does not account for a person's body composition, which is composed of body fat, lean muscle mass, and water mass. There have been reports of athletes being classified as obese based on BMI due to having a high amount of lean muscle mass. However, they would likely not be at an increased risk of health complications due to living an active lifestyle and eating healthy diets. Although BMI can be an indicator of overall health status in many people and is still used in many research studies, it is important that you discuss your BMI results in combination with other measures of health such as bloodwork with your doctor. Your BMI is only one assessment of your health and it is possible to be healthy with a BMI in the overweight range. Similarly, it is possible to have health complications, including signs of metabolic syndrome, with a normal range BMI.

Another measure of obesity that has more support for its accuracy is waist circumference. Having a high amount of body fat on your abdomen will give a high waist circumference. Evidence shows that waist circumference has more support than BMI for being a predictor of cardiovascular disease and type 2 diabetes. Waist circumference is measured by placing a measuring tape around your umbilical region of your abdomen and measuring the distance around your waist. A waist circumference of >102 cm for men and >88 cm for women is considered high risk for cardiovascular disease and metabolic syndrome.

If you have both an elevated BMI and waist circumference, you may be at risk for health complications and this can also worsen your HS. A study of people who had a BMI of greater

than 30 showed that about 18% had HS compared to a prevalence of 1-4% in the general population.[2] Previous studies have shown that between 20% and 75% of HS patients may be overweight or obese.[1-5]

Obesity is thought to worsen HS due to increased sweating, skin friction, and the number of skin folds. Another explanation for this is that insulin resistance is more commonly found in people who are overweight and obese, and this can trigger excessive androgen hormone production, which can worsen HS.

A study on HS patients who lost 15% or more of their body weight showed that about 50% of patients went into clinical remission and another 20% saw improvement in their HS.[2]
If you have an elevated BMI, waist circumference and signs of metabolic syndrome, you may benefit from weight loss and you can discuss resources to support weight loss with your physician.

It is important to remember that while obesity may be a risk factor for HS and it can make HS worse in some cases, obesity alone is not causative of HS. The majority of people who are overweight and obese don't develop HS. People with HS often have a genetic predisposition and a family history of the condition. There are also many HS patients who have a weight in the normal BMI range or are even classified as underweight and they still have HS. Many HS patients report that they have had HS since their teenage years, regardless of their body size.

Additionally, some patients with HS gain weight after onset of the condition because of pain with movement and depression, which can lead to obesity. Some women with HS struggle with weight gain because of PCOS, as excess androgens can increase insulin resistance and make it easier to gain weight.

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 I: Diagnosis, evaluation, and the use of complementary and procedural management. J Am Acad Dermatol. 2019;81(1):76-90. doi:10.1016/j.jaad.2019.02.067
2. Kromann CB, Ibler KS, Kristiansen VB, Jemec GB. The influence of body weight on the prevalence and severity of hidradenitis suppurativa. Acta Derm Venereol. 2014;94(5):553-557. doi:10.2340/00015555-1800
3. Shalom G, Freud T, Harman-Boehm I, Polishchuk I, Cohen AD. Hidradenitis suppurativa and metabolic syndrome: a comparative cross-sectional study of 3207 patients. Br J Dermatol. 2015;173(2):464-470. doi:10.1111/bjd.13777
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Metabolic Syndrome

Metabolic syndrome is defined as having three or more of the following: obesity, increased blood glucose, which refers to the sugar level in the blood, increased triglycerides (fat in the blood), low high-density lipoprotein (HDL) or a low level of the "good" cholesterol, and elevated blood pressure. A high blood pressure reading is when blood pressure measures at least 140/90. Research suggests that patients are more likely to have developed HS at a younger age if they have both HS and metabolic syndrome.

Research has shown that metabolic syndrome in more common in HS patients compared to the general population. In one study, about 34% of HS patients met criteria for a diagnosis of metabolic syndrome compared to 17% of people without HS.[1]

If you have not had recent bloodwork done and have recently been diagnosed with HS, it may be beneficial to visit your family physician for routine bloodwork, which often includes screening tests for cholesterol, triglycerides, and blood glucose. You should also have your blood pressure measured. This is particularly important if you have a family history of heart disease or diabetes, as metabolic syndrome is a risk factor for those conditions. Metabolic syndrome is also more common in women who have PCOS.

Signs of metabolic syndrome:

1) Obesity
2) Increased fasting blood glucose
3) Increased triglycerides
4) Low HDL cholesterol
5) Elevated blood pressure

1. Shalom G, Freud T, Harman-Boehm I, Polishchuk I, Cohen AD. Hidradenitis suppurativa and metabolic syndrome: a comparative cross-sectional study of 3207 patients. Br J Dermatol. 2015;173(2):464-470. doi:10.1111/bjd.13777

Diabetes

Diabetes mellitus is a condition in which your body either does not produce enough insulin to help your cells use glucose from the blood or your cells become insensitive to insulin and your pancreas produces an excessive amount of insulin to compensate.

Type 1 diabetes occurs when your body has an autoimmune response against the insulin producing cells of the pancreas, causing these cells to be destroyed and preventing your body from making insulin. Type 1 diabetes is often called "insulin-dependent diabetes," as patients are required to take supplemental insulin in order to survive. Type 1 diabetes tends to occur in younger patients but can occur at any age.

Type 2 diabetes occurs when your pancreas is able to make insulin, but your cells become less sensitive to insulin over time. Genetics, hormones, diet, and other lifestyle factors can play a role in this process. Insulin normally stimulates cells to take up insulin, but in cases where blood glucose levels are consistently high, your cells become unable to take up more glucose and they

allow for less activation by insulin. This leads to both high blood glucose levels and high insulin levels, as the pancreas makes more insulin when it senses that your blood glucose levels are high. Medications that help the body to become more sensitive are often the first treatments prescribed to patients with type 2 diabetes. This type of diabetes tends to occur in patients who are older as it can be associated with long-term intake of a diet that is high in refined carbohydrates.

Studies have shown that about 11-19% of HS patients have type 2 diabetes compared to 6-7% of people without HS.[1,2] Type 2 diabetes is more common in people who have severe HS compared to mild HS. Type 1 diabetes is also more common in HS patients compared to the general population, however, type 1 diabetes is more often diagnosed years before someone develops HS rather than after HS has been diagnosed.[3]

Symptoms of diabetes include excessive thirst and urination, as well as weight loss and these symptoms occur more rapidly in patients with type 1 diabetes. If you have these symptoms or have a family history of diabetes, you may want to visit your doctor to have your blood sugar levels tested.

1. Shalom G, Freud T, Harman-Boehm I, Polishchuk I, Cohen AD. Hidradenitis suppurativa and metabolic syndrome: a comparative cross-sectional study of 3207 patients. Br J Dermatol. 2015;173(2):464-470. doi:10.1111/bjd.13777
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3. Kjærsgaard Andersen R, Jørgensen IF, Reguant R, Jemec GBE, Brunak S. Disease Trajectories for Hidradenitis Suppurativa in the Danish Population. JAMA Dermatol. 2020;156(7):780-786. doi:10.1001/jamadermatol.2020.1281

Inflammatory Arthritis

Certain types of arthritis, which is an inflammatory disease of the joints, have been found to occur more frequently in patients with HS than in individuals who do not have HS. These types include ankylosing spondylitis, psoriatic arthritis, and rheumatoid arthritis.[1] Inflammatory arthritis can involve the spine and result in chronic low back pain or it can involve joints like the knee, foot, or hip. Although studies have shown that there is an increased risk of inflammatory arthritis in HS patients, this risk is overall very low. In a study that followed patients for a year and a half, 0.06% of HS patients developed ankylosing spondylitis compared to 0.036% of non-HS patients, 0.084% of HS patients developed psoriatic arthritis compared to 0.058% of non-HS patients, and 0.454% of HS patients developed rheumatoid arthritis compared to 0.386 of non-HS patients.[1] Although the rates of inflammatory arthritis in HS patients are higher than the rates of arthritis in the general population, the incidence of new cases of arthritis in HS patients is very low and this is not something that you need to worry about if you have HS and do not have any joint symptoms.

If you have symptoms such as joint pain or stiffness that last for longer than a few weeks, are not the result of an injury, and get worse over time, you should follow-up with your physician. An x-ray can confirm abnormalities in the joints and bloodwork will also likely be ordered, as

there are certain antibodies that are associated with different types of arthritis. You should let your physician know if you have a family history of arthritis, as certain types of arthritis more commonly occur in people with a family history. You should also let your doctor know if you have a family or personal history of psoriasis, which is an inflammatory skin condition that has an associated subtype of arthritis, called psoriatic arthritis.

1. Schneeweiss MC, Kim SC, Schneeweiss S, Rosmarin D, Merola JF. Risk of Inflammatory Arthritis After a New Diagnosis of Hidradenitis Suppurativa. JAMA Dermatol. 2020;156(3):342–345. doi:10.1001/jamadermatol.2019.4590

Celiac Disease

Celiac disease is an autoimmune disease that causes the body's immune system to become sensitized against gluten and produce an immune response. This immune response causes destruction of the cells in the gastrointestinal tract when foods that contain gluten are eaten and can lead to symptoms such as bloating, diarrhea, fatigue, anemia and weight loss. This condition is estimated to impact up to 1% of the population.

There have been previous case reports of two HS patients who were diagnosed with celiac disease and after going on a gluten free diet, experienced significant improvement of their HS.[1] Although celiac disease does not cause HS and the majority of HS patients have not been found to have celiac disease, you should discuss the possibility of having celiac disease with your physician if you have digestive symptoms that persist for many weeks or if you have a known family history of celiac disease. An antibody blood test can be done to rule out the possibility of celiac disease and determine if further testing should be done. However, it is important to not remove gluten from your diet before being tested for celiac disease, as you can get a false negative test if you have already eliminated gluten from your diet.

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Acne

Having a past or current history of acne is common in patients with HS. HS patients are 3 times more likely to report a history of different types of acne compared to people without HS.[1] This includes acne subtypes such as acne vulgaris, which is the most common type of acne that occurs in up to 85% of the general population, and more severe types of acne such as acne conglobata (a type of cystic acne) and acne fulminans.[1-3]

In rare cases, patients who have HS and cystic acne may have other conditions within a group of conditions that dermatologists call the 'follicular occlusion tetrad.'[4] This refers to a cluster of four skin conditions linked to the plugging of the hair follicle. These conditions are HS, pilonidal sinus/cysts, dissecting folliculitis of the scalp, and acne congloblota. Your dermatologist may want to examine your scalp and check for signs of a pilonidal sinus (which is a hole in the skin at the top of the buttocks that can be surgically repaired), to screen for these other conditions associated with HS.

Acne shares some similar characteristics with HS. Both conditions involve occlusion of hair follicles and are the result of non-infectious, inflammatory response created by the body's own immune system.[1,2] Both acne and HS can be worsened by excessive androgen hormones. However, acne vulgaris is a separate condition from HS, as it occurs in different regions of the body, such as the face, chest and back and is an overreaction by the body against Cutibacterium acnes, which is a type of bacteria that is normally present on the skin.[2] This bacterium has not been shown to play a role in HS. In addition, some common treatments that are highly effective for treating acne, such as isotretinoin (also known as Accutane), have not shown the same efficacy in treating HS in research studies.[1]

If you also struggle with acne in addition to HS, there are some treatment options that your dermatologist can recommend to improve both your acne and your HS. For women, common treatment options include certain birth control pills and spironolactone, an anti-androgen medication. Topical and oral retinoids can be trialed to treat co-existing HS and acne, though these medications may be more effective for managing acne rather than HS. HS treatments will be discussed in more detail in chapter 7.

1. Phan K, Charlton O, Smith SD. Hidradenitis suppurativa and acne vulgaris and conglobata—systematic review and meta-analysis. Biomed Dermatol. 2019;3:12. https://doi.org/10.1186/s41702-019-0045-z
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3. Scheman AJ. Nodulocystic acne and hidradenitis suppurativa treated with acitretin: a case report. Cutis. 2002;69(4):287-288.
4. Vasanth V, Chandrashekar BS. Follicular occlusion tetrad. Indian Dermatol Online J. 2014;5(4):491-493. doi:10.4103/2229-5178.142517

Pyoderma Gangrenosum (PASH)

Pyoderma gangrenosum is a skin condition that appears as ulcerated red nodules, can be very painful and most commonly occurs on the legs. Pyoderma gangrenosum is also known to be associated with Crohn's disease and occurs in 1-3% of people who have IBD.[1]

A specific rare genetic mutation can cause a syndrome called PASH, which stands for pyoderma gangrenosum, acne, and hidradenitis suppurativa.[2]

The overall risk of HS patients developing PG is 0.18% compared to 0.01% of the general population. However, the risk of developing PG is mainly increased in HS patients with Crohn's disease. PG occurs in about 3.68% of patients with both HS and CD but only 0.12% of HS patients who do not have Crohn's disease.[3] If you do not have IBD, your risk of developing PG in addition to HS is very low.

1. States V, O'Brien S, Rai JP, et al. Pyoderma Gangrenosum in Inflammatory Bowel Disease: A Systematic Review and Meta-Analysis. Dig Dis Sci. 2020;65(9):2675-2685. doi:10.1007/s10620-019-05999-4
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3. Tannenbaum R, Strunk A, Garg A. Overall and subgroup prevalence of pyoderma gangrenosum among patients with hidradenitis suppurativa: A population-based analysis in the United States. J Am Acad Dermatol. 2019;80(6):1533-1537. doi:10.1016/j.jaad.2019.02.004

Squamous Cell Carcinoma

One risk of hidradenitis suppurativa that has not been treated for many years is an increased risk of developing squamous cell carcinoma (SCC). This is a type of non-melanoma skin cancer that is commonly associated with sun damage but can also result from inflammation that occurs with chronic wounds that do not fully heal. This condition is relatively uncommon and about 4.6% of HS patients will get this in their lifetime, but it can turn to an aggressive form of cancer and spread to other parts of the body if it does occur.[1,2] This condition most commonly occurs in male patients and patients who have HS in the anogenital and buttock regions. This condition develops after many years of having HS that is not well-controlled.

If you notice any changes in your HS lesions that look different from other lesions and have features such as an irregular border or a raised, scaly appearance, you should visit a dermatologist to have a skin exam. If you have active HS, it may be beneficial to visit your dermatologist at least once every year or two for a skin exam to ensure that there are no concerning signs. Your dermatologist may choose to do a biopsy if they think that there is a risk of SCC.

SCC appears to occur in a minority of HS patients and may be prevented from early and effective treatment of HS to reduce the number of inflammatory lesions that you have. Smoking is an additional risk factor for SCC, so it is best to discontinue smoking if possible to minimize your risk.

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2. Sachdeva M, Mufti A, Zaaroura H, et al. Squamous cell carcinoma arising within hidradenitis suppurativa: a literature review [published online ahead of print, 2021 Jun 2]. Int J Dermatol. 2021;10.1111/ijd.15677. doi:10.1111/ijd.15677

Depression and Anxiety

Increased rates of mental health conditions, such as depression and anxiety have been associated with HS. A recent large study showed that up to 17% of HS patients met diagnostic criteria for depression and 5% met diagnostic criteria for generalized anxiety.[1] Factors that may contribute to these mental health conditions include worries about ones' health, stress of managing a chronic illness, pain, and body image concerns. Symptoms of depression and anxiety, as well as advice for improving your mental health while dealing with HS will be discussed in chapter 11.

1. Machado MO, Stergiopoulos V, Maes M, et al. Depression and Anxiety in Adults With Hidradenitis Suppurativa: A Systematic Review and Meta-analysis. JAMA Dermatol. 2019;155(8):939–945. doi:10.1001/jamadermatol.2019.0759

Should I be Concerned about Developing Another Medical Condition?

Although it is common to have other medical conditions in addition to having hidradenitis suppurativa, this is not the case with all HS patients. Some patients only have HS and otherwise have no other medical conditions. The goal of this chapter is to help people with HS and their healthcare providers to be aware of some of the other conditions that occur more frequently in HS patients, so that you are better prepared to seek help if you develop symptoms. Knowing if you have another chronic medical condition can also help your dermatologist to recommend treatments that are more likely to help your overall health, as there is overlap in treatments used for conditions such as inflammatory bowel disease, PCOS, inflammatory arthritis and HS. However, if you have had recent normal bloodwork and are not having symptoms of these conditions, you do not necessarily need to worry about developing another condition or seek out diagnostic testing, as each one of these conditions occurs in a minority of the HS patient population. Some routine screening bloodwork ordered by your family physician every year or every few years may be beneficial to ensure that you have not developed any health concerns.

CHAPTER 6

Written by: Leah Johnston, Susan Poelman, Elizabeth O'Brien

Lifestyle Modifications for HS: Diet, Exercise and Smoking Cessation

Chapter Introduction

After receiving a diagnosis of HS and deciding on a treatment plan, many people wonder if there are any other changes that they can make in their daily lives to help improve their HS. A topic that many people with HS take into consideration is dietary modification. Although there are no specific foods that are known to trigger HS flare-ups in all patients, there is some evidence to suggest that diet may play a role in HS and some patients report that making dietary changes can help to improve their symptoms. Weight loss may also be beneficial for individuals who are overweight or obese. This chapter will provide an overview of general nutrition advice for eating a healthy diet, as well as specific diets that have been studied in HS patients and the scientific evidence supporting them.

Other lifestyle changes to manage HS can include modifying exercise to avoid irritating your skin, wearing clothing that limits friction in skin folds, avoiding shaving, and other at-home care techniques. Tracking factors that may trigger flare-ups can also be useful to help reduce the frequency of flare-ups. For some people, HS can also interfere with intimacy and daily work activities, and there are strategies that can help you to deal with challenges that you may experience.

If you currently smoke, it can be highly beneficial for your HS to quit smoking and advice for smoking cessation will also be discussed in this chapter.

Diet and HS

What is a healthy diet for HS?

For many people, understanding how to eat healthy is a challenge, as it can feel as though almost every few weeks, there is a new fad diet being promoted by celebrities and the fitness industry. For people with HS, this is even more of a challenge, as there is significant speculation by both patients and physicians that diet may play a role in HS. When Googling 'hidradenitis suppurativa and diet,' the results show many posts from bloggers with HS who swear by certain diets or avoiding certain foods. Although there have not been any large randomized control trials looking at diet and HS, some studies have suggested that certain dietary modifications may improve HS. However, not all patients in these studies improved and some noticed their HS worsening or did not have any change with specific diets. It is important to be cautious when starting any new diet and it may be useful to speak to a dermatologist or a registered dietitian with experience in helping patients with inflammatory conditions. If you have HS and also have another medical condition, such as diabetes or Crohn's disease, it is even more important to seek professional dietary advice as these conditions could complicate your nutrient intake and overall health. The goal of this section is to provide an overview of general nutrition concepts as well as specific dietary strategies that have been studied in HS or have been reported by other patients to be beneficial. This can help people with HS to decide if dietary modification is a treatment strategy that they would like to pursue. This information is also beneficial for healthcare practitioners who work with HS patients, as diet counselling may be beneficial for some patients.

General Principles of Healthy Eating

Most health experts agree that lowering the amount of processed foods is a good place to start if you are thinking of making changes to your diet. Processed foods are often pre-packaged and contain ingredients on the label that you do not recognize. An example of reducing processed foods in your diet would be to substitute a cup of fruit and some nuts instead of a granola bar for a snack. Packaged foods often contain added sugars and preservatives which can contribute to inflammation.[1] If a food is something that will expire in a few days if you don't eat it, it is more likely to be unprocessed and not contain inflammation-inducing chemicals.

A diet that contains an adequate amount of protein is something that many dermatologists recommend to patients with chronic wounds and this will likely help your HS and your overall health. In chronic wound patients, a dietary deficiency in protein has been linked with lower immune function, poorer wound healing, and wound complications.[2] HS wounds that have been present for a long period of time can behave similarly to other types of chronic wounds. Increasing protein intake is recommended by physicians after surgery or significant illness to improve recovery.[3]

Adequate protein intake is essential in order to maintain muscle mass and promote wound healing. Higher protein diets are also very useful for increasing satiety from meals, which can help people to feel fuller longer and can be helpful for people who are trying to lose weight.[4] The minimum daily protein intake to prevent a protein deficiency is about 0.8 g per kilogram per day of body weight, and ideally people who are active should be eating 1.2 to 2.2 g of protein per kg per day to help maintain or gain muscle mass.[5-7] People who are active should aim for a protein intake at the higher end of this range. Athletes may require an even higher protein intake.

For example, an individual that weighs 70 kg should eat a minimum of 56 g of protein per day, and should aim to eat between 84 g and 154 g of protein per day, depending on activity level and desired daily caloric intake.

Eating a diet that has a sufficient amount of protein, in combination with weight lifting and resistance training exercises, can help to increase lean muscle mass. Increasing lean muscle mass has been shown in research to help reduce insulin resistance, which can help improve how your body uses energy from carbohydrates.[8,9] Reducing insulin levels can also help reduce androgen hormone levels, which may improve your HS.[10]

Intuitive eating is another approach to healthy eating that has strong support from research.[11,12,13] Intuitive eating is not a diet, but is a mindfulness-based approach to eating for wellness and being in tune with your body's needs. There are no specific dietary restrictions on any particular foods, other than for medical reasons, such as allergies and intolerances. Intuitive eating involves increasing awareness of your body's hunger cues so that you eat when hungry and are able to stop eating once you are full. This approach also focuses on how well you feel in response to eating particular foods and adjusting your dietary intake accordingly. Intuitive eating has been associated with long-term weight stability, having a lower BMI and improved psychological health compared to traditional dieting.[11,12,13] Those who practice intuitive eating may also tend to eat more fruits and vegetables compared to people who follow diets.[14]

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Specific Diets for HS

As there have been very few scientific studies published on diet and HS, it is a challenge for dermatologists to make specific dietary recommendations. Small studies have found that elimination of refined carbohydrates and sugars, dairy products, and brewer's yeast to be helpful in reducing inflammatory lesions in some patients. However, not all patients will see improvement when making any given dietary modification and there is no one food ingredient that universally causes HS. There is currently no expert consensus on a "hidradenitis suppurativa diet." This is particularly important to understand when reviewing books and other resources that claim to have a diet that will cure HS, especially if these resources have not been peer reviewed by medical experts and if you have to pay to access this information. It is also important to be careful in planning your diet if you choose to eliminate certain foods, as diets which eliminate multiple food groups may put you at risk for nutrient deficiencies. This section has included evidence from studies that have been done so far looking at the role of diet and HS to help guide which dietary modifications are most likely to be beneficial for people with HS.

Low Dairy and Dairy-Free Diets

Evidence suggests that dairy products may worsen HS. Common dairy products include milk, cheese, yogurt, and butter. A previous study of 47 HS patients found that 83% of patients who followed a dairy-free diet showed improvement in their HS, with no patients showing worsening of HS during the study period.[1] Patients did not restrict their overall dietary glycemic load during the study, suggesting that dairy products may play an independent role in HS.

The mechanism of how HS may be worsened by dairy products can be explained by the influence of dairy on hormone levels.[2] As discussed in previous chapters, high levels of androgen hormones can worsen HS. Dairy products contain proteins called casein and whey, which indirectly increase activity of androgen hormones by increasing levels of insulin and insulin-like growth factor. This increases release of androgen hormones and also allows for androgen receptors to be more easily activated by androgen hormones at the hair follicles. Dairy products also contain natural androgens, which contributes to increasing androgen levels. Dairy products have also been found to play a role in worsening acne through a similar hormonal mechanism.[3]

If you are thinking of changing your diet to lower your consumption of dairy products, it may be helpful to start by making small changes to your current dairy consumption. In studies on milk consumption in acne patients, acne was worsened by a high consumption of skim or low-fat milk and to a lesser extent, whole milk.[4,5,6] Skim milk tends to have a higher concentration of whey protein compared to other dairy products, which produces a more prolonged elevation in insulin levels and can contribute to raising androgen hormone levels.[7] It may be beneficial for your HS to substitute a higher fat percentage milk instead of skim milk. Unsweetened, non-dairy milk substitutes such as almond milk, coconut milk, and oat milk are also good choices and they typically do not contain whey and casein. If you enjoy milk in your coffee or tea, most cafés have milk substitutes as options.

Similar to how dairy products that are high in whey protein may worsen HS, protein powders containing whey protein that are commonly used in protein smoothies may also worsen your HS. Studies have shown that consumption of protein smoothies and caloric supplements containing whey protein has been associated with the onset of acne in athletes.[8,9] It may be best to avoid these products or consider purchasing protein powers that do not contain whey protein.

Yogurt and cheese have not been associated with a worsening of acne in previous studies and although this has not been studied in HS, removing these dairy products from your diet may be unnecessary to see improvements in your HS.[6]

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Low Glycemic Index Diets

Foods that are high in sugar and refined carbohydrates are known as foods with a high glycemic index. High glycemic index foods can cause a rapid increase in blood glucose levels upon consumption, which triggers an increase in insulin. If you frequently consume high glycemic index foods over time, increased levels of insulin and insulin-like growth factor can increase your androgen hormone levels, which may worsen your HS.[1] Studies in acne patients have found that following a low glycemic index diet reduces levels of insulin-like growth factor, which has been found to worsen acne and is also thought to worsen HS.[1,2,3]

Foods that are low on the glycemic index include eggs, bacon, meat, fish, nuts, legumes, most fruits and vegetables, and some whole grains.[4] Foods that are high on the glycemic index include baked goods, refined bread products, fruit juices, and sweetened beverages such as pop and soft drinks. It may be beneficial to reduce consumption of high glycemic index foods to improve your HS.

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Low Carbohydrate Diets

Similar to low glycemic index diets, low carbohydrate diets also aim to reduce consumption of sugar and refined carbohydrates. Previous studies have found that a small group of HS patients saw improvement in their HS symptoms when they went on a low carbohydrate diet.[1] A low carbohydrate diet involves reducing foods that contain high amounts of sugar and carbohydrates and total daily consumption of carbohydrates is typically less than 50-100 g per day. The ketogenic diet is a specific type of low carbohydrate, high fat diet, where the net daily amount of carbohydrates consumed is 20 g or less, with 5-10% or less of total daily caloric intake coming from carbohydrates, 70-75% from fat and 20-25% from protein.[2,3] Although the ketogenic diet has not been formally studied in HS, some HS patients report improvement in HS symptoms upon switching to this diet. The ketogenic diet has been studied in women of childbearing age with PCOS, which is more common in HS patients.[5] After following a ketogenic diet for 6 months, women with PCOS had reductions in testosterone and insulin levels, as well as improved levels of hormones that regulate the menstrual cycle and fertility. Many participants also experienced significant weight loss. Other studies have deemed ketogenic diets to be safe to stay on long-term, with improvements in blood glucose levels, triglycerides, and cholesterol.[6] Some people with type 2 diabetes have been able to reverse their diabetes and reduce the number of medications they take daily by following a ketogenic diet.[7]

A low carbohydrate or ketogenic diet may be beneficial for managing your HS due to reduced activation of hair follicles by androgens such as testosterone and insulin. A similar hormonal mechanism is used to explain how ketogenic diets may be beneficial for acne management.[8] If you are overweight or obese, weight loss may also help to reduce friction in areas of the body where you have HS.

Although reducing carbohydrate intake can be a challenge, many people find this to be doable by starting with small changes in their diets. For example, instead of ordering rice, potatoes, or bread as a side dish with a restaurant meal, you could substitute a side salad or low carbohydrate vegetables. Many restaurants are also able to substitute lettuce wraps instead of buns on burgers and sandwiches. Another simple switch is to drink coffee without adding sugar and choose low carbohydrate coffee orders, such as an Americano coffee instead of a sugary latte.

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Wheat and Brewer's Yeast Elimination Diet

Products which contain wheat and brewer's yeast include bread and baked goods, fermented cheeses, soy sauce, vinegar, black tea, mushrooms, beer and wine.[1] Brewer's yeast is mainly composed of a yeast called Saccharomyces cerevisiae. Some people can develop an immune response against this yeast, and an antibody blood test can be done to see if your body reacts to this yeast. The specific name for the antibody tested for is the anti-Saccharomyces cerevisiae antigen (ASCA) IgG antibody. An association between ASCA antibodies has been found in Crohn's disease and other autoimmune diseases including type 1 diabetes and rheumatoid arthritis.[2] An increase in immune system activation from consuming food products that your immune system reacts to may play a role in the inflammation seen in HS.

A study of a brewer's yeast elimination diet was done in 12 HS patients who had a positive antibody test against brewer's yeast.[1] All patients in the study saw improvement in their HS after 12 months on this diet. Patients who consumed brewer's yeast after elimination saw a return of HS flare-ups.

One limitation of this study is that there is a small number of patients who were included in the study and all patients included had a positive antibody test.[1] More research is needed to determine how common it is for patients with HS to have a positive antibody test and if improvement on a brewer's yeast diet occurs in all HS patients or only those who have had a positive test.

It is recommended that you speak to your physician prior to eliminating brewer's yeast from your diet. Brewer's yeast may not worsen HS in all cases and other studies have found brewer's yeast supplementation to be beneficial in improving glucose tolerance and insulin levels in people who have type 2 diabetes.[3]

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Mediterranean diet

The Mediterranean diet is a diet that consists of fresh fruit and vegetables, whole grains, legumes, nuts, eggs, fish, seafood, poultry, and extra virgin olive oil.[1] Red wine and dairy are included in low to moderate weekly amounts on this diet. Processed foods that are high in sugar, refined carbohydrates, and preservatives such as processed meats are reduced or eliminated. Research has shown that following a Mediterranean diet can reduce risks of developing heart disease and some types of cancer.[2] In a previous study done in Italy that compared the diets of 41 people with HS to 41 people who did not have HS, researchers found

that people with HS ate fewer foods that are part of the Mediterranean diet.[3,4] Although no studies have been done to investigate whether or not people with HS experience improvement in their symptoms, an association was found between the severity of HS and following the Mediterranean diet.[4] People who consumed fewer Mediterranean diet foods tended to have more severe HS.[4] It may be beneficial for your HS to incorporate more Mediterranean diet foods into your diet.

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Autoimmune Protocol Diet

There have been reports by HS patients that following an Autoimmune Protocol Diet (AIP) has improved their HS symptoms.[1] The AIP is a frequent topic of discussion in HS discussion forums and social media platforms such as Reddit. There are some published books that are available for sale online which focus on using the AIP diet to manage HS.

The AIP involves an initial dietary elimination phase of all foods containing grains, gluten, seeds, nuts, legumes, nightshades (tomatoes, peppers, paprika, potatoes), dairy, eggs, coffee, alcohol, refined sugar, oil, and added preservatives.[2] The AIP also encourages participants to avoid non-steroidal anti-inflammatory medications and encourages sleep, exercise, and reduction of stress. After improvement of symptoms is achieved, patients then re-introduce foods that were previously eliminated and seek to identify if particular foods cause flare-ups of their medical conditions.

There has been one previous study that suggests that autoimmune protocol diets may be beneficial in managing Crohn's disease, which involves an auto-inflammatory mechanism that is similar to HS.[2] This study found that 6 out of 7 patients had reduced inflammatory findings and symptom improvement on colonoscopy after 11 weeks of following the AIP diet. However, no control group was used in this study and 2 of the patients who saw improvement recently started biologic therapy, which may have contributed to improvement and confounded the study results. Another study of the AIP was done in patients with autoimmune thyroid disease and while no changes were seen in thyroid hormone levels, markers of systemic inflammation improved on the AIP diet.[3]

While the reduction in markers of inflammation appears promising, it is difficult to determine whether these results are due to following the AIP diet as a whole or if the results mainly stem from specific aspects of the AIP. A likely explanation for the reduction in inflammation seen in

these two studies is that it is the result of eliminating processed foods and foods that are high in refined sugars and carbohydrates, in addition to adopting other healthy lifestyle changes such as regular exercise and improved sleep hygiene.

It is important to note that no research studies have been done to investigate the effects of the AIP in HS patients. In addition, no studies have been done to compare the AIP protocol diet to other diets, such as low-dairy and low glycemic index diets. Further study in randomized control trials is needed to determine if the AIP diet has any additional benefits compared to other diets before it can be recommended to patients with HS or other inflammatory conditions.

One concern with following the AIP diet is that due to the large number of foods and ingredients that are typically eliminated with this diet, nutrient deficiencies may develop. In addition, a diet that restricts many foods may be harmful to your quality of life as you may be unable to enjoy meals with family and friends. If you are choosing to go on an AIP diet, you should consult your dermatologist or a registered dietitian, as they can help you to monitor your symptoms and plan your dietary intake so that you are less likely to develop a nutrient deficiency.

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Weight Loss Diet

Dietary modifications which result in weight loss may be beneficial for HS.[1,2] Weight loss is most likely to benefit HS patients who are overweight or obese based on measures of BMI, abdominal circumference and body fat percentage. In a study of HS patients who underwent bariatric surgery and lost 15% or more of their body weight, 49% had complete resolution of their HS symptoms and 20% had a reduction in symptom severity.[1] Weight loss is thought to improve HS through a reduction in friction in the skin folds as well as a reduction in overall systemic inflammation.[1,2] However, it is important to note that not all HS patients are overweight or obese and additional weight loss in patients who are already at a healthy weight may not provide any relief of HS symptoms.

If you would like to try losing weight to improve your HS, it may be useful to speak to your dermatologist. They may be able to offer advice or refer you to a healthcare professional such as a dietitian that can give individualized recommendations for dietary and lifestyle modifications to support weight loss and improve your overall health. In general, weight loss is more likely to be successful if you focus on making changes that are sustainable in the long term. A modest calorie deficit of 500-1000 calories per day will help you to lose weight without putting you at risk of nutrient deficiencies and other health complications.[3] One challenge that many people

experience when going on a diet is making drastic changes which produce short term results, but the changes made are unsustainable in the long-term. This often leads to regaining the weight that was originally lost or even additional weight gain above their starting weight.[4] To avoid this problem, steady weight loss over an extended period of time and adopting health-promoting habits such as consuming a diet low in processes foods and increasing physical activity is the safest and most effective approach for losing weight.[4]

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Dietary Supplements

There is some evidence to suggest that dietary supplements and vitamins may be beneficial for managing HS. Supplements that have supporting evidence from clinical studies include zinc, vitamin D, and myo-inositol.[1] Although not yet studied in HS patients, curcumin (an ingredient found in turmeric supplements) and omega-3 fatty acids may also be beneficial.[1]

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Zinc

Zinc has been shown to be effective at both reducing overall inflammation and reducing the activity of androgen hormones at hair follicles.[1] Previous studies comparing blood levels of zinc in people with HS compared to people who did not have HS found that people with HS are significantly more likely to be deficient in zinc. Zinc deficiency was also more pronounced in people with more severe HS.[2] One clinical study with 22 patients that had Hurley stage I or II HS found that 14 patients experienced partial improvement and 8 patients experienced complete remission of their HS symptoms after taking 90 mg zinc gluconate daily.[3] Another study found that biopsies of HS-affected areas of skin showed reduced levels of markers of inflammation after 3 months of daily supplementation with 90 mg of zinc.[4]

A major side effect of zinc supplementation is gastrointestinal upset, which includes symptoms such as nausea, vomiting and diarrhea.[1,3] Zinc also competes with copper for absorption in the gastrointestinal tract, so chronic zinc supplementation may lead to a copper deficiency.[5,6] Side effects of a severe copper deficiency can include anemia, low white blood cell counts, and nerve damage.[5,6] One case was reported of an HS patient who developed severe anemia

and copper deficiency after taking 100 mg of zinc daily for 6 years.[6] Some experts recommend taking a copper supplement at a different time of day while you are taking a high-dose zinc supplement to prevent a copper deficiency.[7] The recommended dose of copper is 2 mg for every 50 mg of zinc.[7] After achieving complete remission on 90 mg per day of zinc therapy, patients in the zinc supplementation clinical study were able to reduce their dosage of zinc to an average maintenance dose of 50 mg of zinc per day.[3] It may be best to reduce your zinc intake to a lower dose after a few months of taking a zinc supplement and have your doctor periodically monitor blood cell counts and copper levels with bloodwork.[5]

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Myo-Inositol

Myo-inositol is a sugar alcohol supplement that has been researched in PCOS management. Although this supplement is classified as a sugar alcohol, it does not tend to raise blood glucose levels the way that sugar does and therefore it does not produce an increase in insulin levels. Current research suggests that this supplement may actually be beneficial in reducing insulin resistance and this can also help to reduce excess androgen hormone levels.[1]

Due to the role of androgen hormones in HS as well as the increased prevalence of PCOS in women who have HS, one study has investigated supplementation with myo-inositol (MI).[2] The group of patients who took a supplement containing 2000 mg of myo-inositol, as well as folic acid and liposomal magnesium for 6 months experienced significant improvement compared to the control group.[2] Women who have both PCOS and HS may benefit from myo-inositol supplementation.

1. Unfer V, Facchinetti F, Orrù B, Giordani B, Nestler J. Myo-inositol effects in women with PCOS: a meta-analysis of randomized controlled trials. Endocr Connect. 2017;6(8):647-658. doi:10.1530/EC-17-0243
2. Donnarumma M, Marasca C, Palma M, Vastarella M, Annunziata MC, Fabbrocini G. An oral supplementation based on myo-inositol, folic acid and liposomal magnesium may act synergistically with antibiotic therapy and can improve metabolic profile in patients affected by Hidradenitis suppurativa: our experience. G Ital Dermatol Venereol. 2020;155(6):749-753. doi:10.23736/S0392-0488.18.06012-1

Vitamin D

Previous research studies have found that vitamin D deficiency may be more common in people with HS compared to people who do not have HS and this deficiency may be more severe in

people with severe HS.[1,2] Vitamin D deficiency may result from inflammation and is more common in the general population during the winter months in areas of the world that are far away from the equator.[1,3] It may be beneficial to take a vitamin D supplement if you have HS, especially during winter months.

1. Silfvast-Kaiser A, Youssef R, Paek SY. Diet in hidradenitis suppurativa: a review of published and lay literature. Int J Dermatol. 2019;58(11):1225-1230. doi:10.1111/ijd.14465
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Turmeric

Curcumin, the active ingredient in turmeric supplements, may be beneficial for reducing inflammation associated with HS.[1] Although turmeric has not been formally studied in HS patients, evidence shows that turmeric can reduce levels of inflammatory proteins, such as TNF-α, which is a treatment target of Humira, a biologic medication approved for HS.[2] In addition, some HS patients have reported improvement in their symptoms after taking this supplement.[1] Research studies are warranted to investigate whether or not turmeric is beneficial in managing HS.

1. Silfvast-Kaiser A, Youssef R, Paek SY. Diet in hidradenitis suppurativa: a review of published and lay literature. Int J Dermatol. 2019;58(11):1225-1230. doi:10.1111/ijd.14465
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Exercise, Clothing and Other Lifestyle Modifications

Exercice

Due to the areas of the body that are affected by HS, which are primarily located within skin folds, exercise can be a challenge for many patients with HS due to pain and skin irritation that occurs with friction. Some people with HS may find that they are able to engage in a high level of physical activity, including activities such running, biking, and other high intensity forms of exercise, while others with more severe HS may not be able to tolerate these activities due to pain and mobility restriction. You may find that exercise is more tolerable on some days and less so on days of HS flare-ups.

Although it can be a challenge, getting regular exercise can be highly beneficial for your overall mental and physical health. Exercise has been shown to help reduce systemic inflammation in people with other chronic inflammatory conditions and this may help manage your HS. In

addition, dealing with a chronic illness can be overwhelming and finding a form of exercise that you enjoy and can engage in regularly can be a significant outlet for stress in your life. It is important to find a form of exercise that works for you and does not cause flare-ups of your HS. An exercise routine that works will be different for each individual person who has HS and it may take some time to figure out the best approach for you. There are some options that can help make exercise more tolerable, including wearing exercise clothing that reduces skin friction, managing sweating if you find that this triggers your HS and choosing lower intensity activities such as swimming, yoga, Pilates, and walking.

Regardless of the type of exercise that you choose to do, clothing that reduces irritation of your skin is essential to prevent HS flare-ups. Although many HS experts recommend loose-fitting clothing for people with HS, this may not be the best choice for exercise. Tight-fitting exercise clothing which prevents direct skin to skin contact, such as rubbing of the inner thighs, is often a good choice for exercise.[1] Moisture-wicking fabrics that contain polyester, spandex or polypropylene are a good choice to help keep your skin dry and reduce irritation during workouts.[2]

Examples of common sportswear clothing brands that make clothing items that can be HS-friendly include Nike, Under Armour, New Balance and Adidas.

Nike mid-thigh length bike shorts and New Balance Fitted T-shirt.
https://www.sportchek.ca/product/nike-sportswear-womens-essential-bike-shorts-color-333340000_01-333340000.html?gclid=EAIaIQobChMIwZ7t5rL68gIVZRitBh01kwalEAQYAiABEgJHv_D_BwE&gclsrc=aw.ds#333340000=333340008 https://www.sportchek.ca/categories/shop-by-sport/training/training-clothing-apparel/womens/product/new-balance-womens-run-accelerate-t-shirt-color-333336868_01-333336868.html#333336868%5Bcolor%5D=333336868_01

Some people with HS report that sweating is a trigger for HS flare-ups. However, this does not necessarily mean that you need to avoid or limit sweat-inducing exercise. There are plenty of treatments that you can try that can help reduce sweating or limit skin irritation from sweating. Over-the-counter antiperspirants for sensitive skin, topical aluminum chloride, oral medications such as oxybutynin, glycopyrrolate and methantheline bromide, and botulinum toxin (Botox) injections can help to reduce excessive sweating.[4,5,6] Topical antiperspirants, hydrating lotions, and zinc oxide creams can also help to reduce skin irritation from chafing during exercise.[7]

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2. Jacoby Zoldan R. 6 Tips That Make Working Out With HS Easier. HealthCentral website. February 4, 2021. Accessed August 4, 2021. https://www.healthcentral.com/article/exercise-with-hidradenitis-suppurativa
3. Collier E, Shi VY, Parvataneni RK, Lowes MA, Hsiao JL. Special considerations for women with hidradenitis suppurativa. Int J Womens Dermatol. 2020;6(2):85-88. Published 2020 Feb 19. doi:10.1016/j.ijwd.2020.02.005
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6. Grimstad Ø, Kvammen BØ, Swartling C. Botulinum Toxin Type B for Hidradenitis Suppurativa: A Randomised, Double-Blind, Placebo-Controlled Pilot Study. Am J Clin Dermatol. 2020;21(5):741-748. doi:10.1007/s40257-020-00537-9
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Clothing

Some people with HS find that wearing tight clothing items, such as jeans or pantyhose can contribute to flare-ups of HS. If you find that this is the case for you, it may be beneficial to wear clothing that is more loose-fitting with soft, breathable fabrics such as cotton, rayon or bamboo.[1] For people who have HS underneath the breasts, bralettes or sports bras may be more comfortable than underwire bras.[2] Wearing mid-thigh length bicycle shorts underneath dresses or skirts may be helpful in reducing skin-to-skin friction in the inner thighs and groin.[2] Some companies, including Knix™, have developed leak-proof underwear as a substitute for menstrual hygiene products, which may be useful for HS patients to manage drainage from active lesions.[3]

1. Collier E, Shi VY, Parvataneni RK, Lowes MA, Hsiao JL. Special considerations for women with hidradenitis suppurativa. Int J Womens Dermatol. 2020;6(2):85-88. Published 2020 Feb 19. doi:10.1016/j.ijwd.2020.02.005
2. Loh TY, Hendricks AJ, Hsiao JL, Shi VY. Undergarment and Fabric Selection in the Management of Hidradenitis Suppurativa. Dermatology. 2021;237(1):119-124. doi:10.1159/000501611
3. Period Underwear. KnixTM Wear Inc. https://knix.ca/collections/period-underwear?loc=HP_B2_Campaign=LP-flatlay-newcolors_LP-Collection_D_Feb22022.

Shaving

Shaving and waxing can be a triggers for HS flare-ups and you may want to avoid using these types of hair removal if you have active HS lesions in the armpits or pubic regions. Laser hair removal (chapter 7) is the preferred method of hair removal for HS, as it also has the benefit of reducing disease activity by destroying hair follicles in areas where HS can occur.

1. Collier E, Shi VY, Parvataneni RK, Lowes MA, Hsiao JL. Special considerations for women with hidradenitis suppurativa. Int J Womens Dermatol. 2020;6(2):85-88. Published 2020 Feb 19. doi:10.1016/j.ijwd.2020.02.005

Menstrual Products

Some women with HS report that using pads during their menstrual periods can contribute to HS flare-ups, due to increased friction on the inner thighs and vulvar area.[1] It may be beneficial to use other menstrual products, such as tampons or menstrual cups, instead of pads during menstruation.

1. Collier E, Shi VY, Parvataneni RK, Lowes MA, Hsiao JL. Special considerations for women with hidradenitis suppurativa. Int J Womens Dermatol. 2020;6(2):85-88. Published 2020 Feb 19. doi:10.1016/j.ijwd.2020.02.005

Alcohol

Currently, no causal relationship has been identified between alcohol use and the onset of HS in previous studies.[1] Some HS patients anecdotally report that alcohol can trigger their HS, while others may find that they can drink alcohol without any changes to their HS. As long as you do not have a history of substance use disorders or conditions that can be impacted by alcohol, such as liver disease, it can be safe to consume alcohol in moderation. Some medications for HS, such as oral retinoids, oral antibiotics, and some pain medications may require that you limit your alcohol intake to avoid unwanted and potentially dangerous side effects.

Heavy alcohol consumption may contribute to systemic inflammation, which could potentially worsen your HS. In women, excessive alcohol consumption has been associated with an increase in androgen hormone levels, which could contribute to HS flare-ups.[2] Inflammatory and hormonal changes that occur with heavy alcohol use are less likely to occur with moderate alcohol intake. Therefore, it is recommended that you follow evidence-based low risk drinking guidelines. For women, it is recommended that you consume no more than 10 standard drinks per week and limit your alcohol intake to a maximum of 2 drinks per day.[2] For men, it is recommended that you consume no more than 15 standard drinks per week and limit your alcohol intake to a maximum of 3 drinks per day.[3]

1. Dauden E, Lazaro P, Aguilar MD, et al. Recommendations for the management of comorbidity in hidradenitis suppurativa. J Eur Acad Dermatol Venereol. 2018;32(1):129-144. doi:10.1111/jdv.14517
2. Sarkola T, Fukunaga T, Mäkisalo H, Peter Eriksson CJ. Acute effect of alcohol on androgens in premenopausal women. Alcohol Alcohol. 2000;35(1):84-90. doi:10.1093/alcalc/35.1.84
3. Canada's Low-Risk Alcohol Drinking Guidelines [brochure]. Canadian Centre on Substance Use and Addiction. 2018. Accessed August 5, 2021. https://www.ccsa.ca/canadas-low-risk-alcohol-drinking-guidelines-brochure

Workplace Accommodations

Some people with HS may require workplace accommodations because of their HS. This can include time off to attend medical appointments, padded chairs in work spaces, flexibility with dress code or uniforms, breaks during shifts to manage symptoms, and flexible time-off or work from home arrangements in the event of an HS flare-up.[1] If you need work modifications to help make working more manageable, you should speak to your employer about your condition. Additionally, your physician can write a letter to your employer in support of your condition and the need for workplace accommodations or medical leave from work.

1. Employer's Guide to Understanding HS and Its Impact. HS Online website. Accessed August 7, 2021. https://www.hsonline.ca/content/dam/hs-redesign/north-america/canada/english/HS-FACT-SHEET-HS-employer.pdf

Intimacy and Sex

Because HS occurs in skin under the breasts, on the inner thighs, in the groin, perianal region and buttocks, some patients may find that HS can impact sexual intimacy. Common issues that HS patients may have with sex include pain with flare-ups and scarring in intimate areas,

odour and/or discharge with active lesions, negative self-image, and fear of a potential partner judging their condition or being concerned about them having an STI.[1] It may be useful for patients to discuss their condition with sexual partners prior to intimacy to reduce their own feelings of anxiety and reassure their partner that their condition is not contagious, is not an infection, is not the result of poor hygiene and their skin has been assessed by a physician. With effective management of HS flare-ups and understanding of one another's needs and challenges with sex, it is absolutely possible for people with HS to have fulfilling and positive sexual relationships.

As with any sexual relationship, it is important to have a discussion with your partner about STI testing and use of protection. A potential concern with HS is that if you have active, open wounds, this could increase your risks of transmitting an STI or contracting one from your partner. This risk can be mitigated by covering wounds with bandages and/or using barrier methods of protection such as condoms. Regular STI testing is recommended, especially if you are in a new relationship or have been sexually active with multiple partners. It is also important to discuss methods for preventing pregnancy, especially if you could potentially become pregnant and are taking a medication for your HS that could cause birth defects if taken in pregnancy.

1. Alavi A, Farzanfar D, Rogalska T, Lowes MA, Chavoshi S. Quality of life and sexual health in patients with hidradenitis suppurativa. Int J Womens Dermatol. 2018;4(2):74-79. Published 2018 Feb 1. doi:10.1016/j.ijwd.2017.10.007

Smoking Cessation and HS

Introduction

Previous studies have shown that smoking is a risk factor for developing HS. Past studies have found that up to 70-75% of people with HS are current smokers and 10-15% are previous smokers.[1] If you have HS and currently smoke, you may benefit from quitting smoking or reducing the number of cigarettes that you smoke per day. However, quitting smoking is a very difficult process for many people, especially if they have been smoking for a long period of their lives. There are medical treatment options, such as oral medications, that have evidence supporting their effectiveness in smoking cessation. In addition, there are many evidence-based strategies that psychologists have found useful for helping their clients to stop smoking, such as cognitive behavior therapy. Support groups and resources are also available to help people quit smoking, and there are some programs specific for HS patients that are developed by pharmacies that dermatologists may refer their patients to for further support. This section will discuss how smoking plays a role in the pathogenesis of HS, medical and psychological options for smoking cessation, and other supportive resources.

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 I: Diagnosis, evaluation, and the use of complementary and procedural management. J Am Acad Dermatol. 2019;81(1):76-90. doi:10.1016/j.jaad.2019.02.067

Why is Smoking Associated with HS?

The exact mechanism of how smoking contributes to HS is uncertain, but studies suggest that a few different factors may be involved. Tobacco in cigarettes contains nicotine, which can increase the amount of bacteria present in skin folds, which are the locations of the body where HS tends to develop.[1] Nicotine has also been shown to increase the levels of inflammatory proteins and the amount of inflammatory keratin that is present in the structure of the hair follicles.[1] Nicotine can also increase the activity of sweat glands by increasing the numbers of receptors which activate the sweat glands.[2,3] Cigarette smoking has also been shown to raise levels of androgen hormones, which are known to be a contributing factor to HS.[4,5] These mechanisms contribute to occlusion, dilation and rupture of hair follicles, which is the mechanism of how HS lesions develop.[6] In people who have a genetic pre-disposition to developing HS, smoking is a risk factor that could lead them to develop symptoms of the disease.

1. Acharya P, Mathur M. Hidradenitis suppurativa and smoking: A systematic review and meta-analysis. J Am Acad Dermatol. 2020;82(4):1006-1011. doi:10.1016/j.jaad.2019.10.044
2. Hana A, Booken D, Henrich C, et al. Functional significance of non-neuronal acetylcholine in skin epithelia. Life Sci. 2007;80(24-25):2214-2220. doi:10.1016/j.lfs.2007.02.007
3. Dessinioti C, Zisimou C, Tzanetakou V, Ntritsos G, Kontochristopoulos G, Antoniou C. A retrospective institutional study of the association of smoking with the severity of hidradenitis suppurativa. J Dermatol Sci. 2017;87(2):206-207. doi:10.1016/j.jdermsci.2017.04.006
4. Jandíková H, Dušková M, Šimůnková K, et al. How smoking cessation influence hormonal levels in postmenopausal women?. Prague Med Rep. 2014;115(12):60-66. doi:10.14712/23362936.2014.6
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6. Hoffman LK, Ghias MH, Lowes MA. Pathophysiology of hidradenitis suppurativa. Semin Cutan Med Surg. 2017;36(2):47-54. doi:10.12788/j.sder.2017.017

Will Quitting Smoking Improve HS?

If you have HS and currently smoke, setting a goal to stop smoking could help to significantly improve your HS. Research studies have found that people who have HS and currently smoke are less likely to see improvements with treatment compared to HS patients who do not smoke or have quit smoking.[1] Because of this, other research has found that people with HS who are not active smokers tend to have a better prognosis compared to those who continue to smoke.[2] Non-smokers report higher rates of disease remission compared to people with HS who actively smoke.[2]

Smoking has also been associated with worsening of other conditions in dermatology that are related to excess androgen hormone activity, including female-pattern hair loss and acne.[3-5] Studies in female-pattern hair loss have found that quitting smoking can help to lower levels of androgen hormones and reduce this type of hair loss.[3] Anti-androgen medications are commonly used to treat HS and have been found to reduce disease activity or even lead to disease remission in some patients.[6] Therefore, if you stop smoking, this could have an effect similar to taking an anti-androgen medication, which could improve your HS. Smoking can also trigger excessive sweating, which is another factor that may worsen your HS.[7-9]

Smoking can also put you at an increased risk for developing severe complications of common treatments for HS. Smoking is a risk factor for developing blood clots in the veins, which can become life-threatening.[10] Birth control pills that have anti-androgenic activity are a treatment option for women with HS, but are often contraindicated in women who smoke due to the potential for increased rates of blood clots. Smoking is also a risk factor for poor wound healing after surgery, which is a concern if you would like to undergo a surgical procedure to manage your HS.[11] Some physicians may require or strongly advise that you quit smoking prior to surgery to avoid the potential for severe complications with impaired wound healing, including infection.

In addition to smoking cessation being beneficial for HS, there are also significant benefits for your overall health. Smoking is associated with significantly increased risks of many different diseases and these diseases are some of the worldwide leading causes of preventable deaths.[12] If you choose to quit smoking, you may be able to prevent diseases such as cancer, chronic lung disease, heart disease, and strokes.[12] Although it is a challenge, stopping smoking is one of the best changes that you can make to benefit your health.

1. Denny G, Anadkat MJ. The effect of smoking and age on the response to first-line therapy of hidradenitis suppurativa: An institutional retrospective cohort study. J Am Acad Dermatol. 2017;76(1):54-59. doi:10.1016/j.jaad.2016.07.041
2. Kromann CB, Deckers IE, Esmann S, Boer J, Prens EP, Jemec GB. Risk factors, clinical course and long-term prognosis in hidradenitis suppurativa: a cross-sectional study. Br J Dermatol. 2014;171(4):819-824. doi:10.1111/bjd.13090
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4. Jandíková H, Dušková M, Šimůnková K, et al. How smoking cessation influence hormonal levels in postmenopausal women?. Prague Med Rep. 2014;115(1-2):60-66. doi:10.14712/23362936.2014.6
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7. Hana A, Booken D, Henrich C, et al. Functional significance of non-neuronal acetylcholine in skin epithelia. Life Sci. 2007;80(24-25):2214-2220. doi:10.1016/j.lfs.2007.02.007
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10. Pomp ER, Rosendaal FR, Doggen CJ. Smoking increases the risk of venous thrombosis and acts synergistically with oral contraceptive use. Am J Hematol. 2008;83(2):97-102. doi:10.1002/ajh.21059
11. McDaniel JC, Browning KK. Smoking, chronic wound healing, and implications for evidence-based practice. J Wound Ostomy Continence Nurs. 2014;41(5):415-E2. doi:10.1097/WON.0000000000000057
12. Toll BA, Rojewski AM, Duncan LR, et al. "Quitting smoking will benefit your health": the evolution of clinician messaging to encourage tobacco cessation. Clin Cancer Res. 2014;20(2):301-309. doi:10.1158/1078-0432.CCR-13-2261

Challenges with Quitting Smoking

Although most people understand that smoking is a risk factor for many different diseases and that there are many health benefits that result from quitting smoking, there are many factors that make smoking cessation a difficult task for many people. Nicotine in cigarettes and other tobacco products can be a highly addictive substance, as it causes release of dopamine, a neurotransmitter, in the reward pathways of the brain.[1,2] Because of this release of dopamine, people who smoke often report feeling more relaxed and having increased cognitive

performance after smoking a cigarette.[3] However, these effects do not last and tolerance to nicotine can develop over time, which causes people to continue smoking and increase the number of tobacco products that they use.[3]

One of the biggest challenges with quitting smoking is that people can experience symptoms of nicotine withdrawal. These symptoms can include feeling dizzy or light-headed, having difficulty sleeping, impaired concentration, cigarette cravings, increased appetite, and feeling anxious, irritable or depressed.[3] Many people who relapse and start smoking again after an initial attempt at quitting do so to alleviate their discomfort from nicotine withdrawal symptoms.

Other factors that can make someone more likely to start and continue to smoke include experiencing significant life stressors, having untreated mental health conditions, and being surrounded by family and friends who actively smoke.[3] Addressing these factors is an important part of any smoking cessation plan.

1. West R. Tobacco smoking: Health impact, prevalence, correlates and interventions. Psychol Health. 2017;32(8):1018-1036. doi:10.1080/08870446.2017.1325890
2. Roh S. Scientific Evidence for the Addictiveness of Tobacco and Smoking Cessation in Tobacco Litigation. J Prev Med Public Health. 2018;51(1):1-5. doi:10.3961/jpmph.16.088
3. Jarvis MJ. Why people smoke. BMJ. 2004;328(7434):277-279. doi:10.1136/bmj.328.7434.277

Medical Treatments for Smoking Cessation

As knowledge has increased in the medical community surrounding the biological basis for nicotine dependence and withdrawal symptoms, new drug treatment options have become available to help people to quit smoking. These options can help to alleviate discomfort that commonly occurs during the withdrawal period, which is most severe during the first month and especially the first week of smoking cessation.[1] Some symptoms, such as nicotine cravings and increased appetite can last months beyond the initial withdrawal period and may require ongoing medical and/or psychological support to prevent relapse.[1] The most common medical treatment options to aid smoking cessation include nicotine replacement therapy and oral medications such as sustained-release bupropion and varenicline.[2,3]

1. Jarvis MJ. Why people smoke. BMJ. 2004;328(7434):277-279. doi:10.1136/bmj.328.7434.277
2. Nagano T, Katsurada M, Yasuda Y, Kobayashi K, Nishimura Y. Current pharmacologic treatments for smoking cessation and new agents undergoing clinical trials. Ther Adv Respir Dis. 2019;13:1753466619875925. doi:10.1177/1753466619875925
3. CAN-ADAPTT. Canadian Smoking Cessation Clinical Practice Guidelines. Canadian Action Network for the Advancement, Dissemination and Adoption of Practice informed Tobacco Treatment, Centre for Addiction and Mental Health. Accessed July 31, 2021. https://www.nicotinedependenceclinic.com/en/canadaptt/Pages/CAN-ADAPTT-Guidelines.aspx

Nicotine Replacement Therapy

Nicotine replacement therapy (NRT) can be prescribed by a physician or purchased over the counter and includes supplemental nicotine in the form of patches placed on the skin as well as nicotine gum, lozenges and inhalers.[1] As some nicotine still enters the body and can reach receptors in the brain, NRT can lessen symptoms of withdrawal during the initial weeks of

smoking cessation.[1] Doses of nicotine can be gradually reduced over time as tolerated, by using progressively lower concentrations in the chosen product over time.

One challenge with NRT is that since it contains nicotine, it can increase risks of heart disease and stroke during the period of use, though short-term use of NRT is preferable to continuing smoking.[1] In addition, nicotine, whether from cigarettes or from NRT could potentially worsen your HS, so this treatment may be best for short-term use in the initial weeks after quitting cigarettes and not as a long-term option for reducing nicotine cravings.[2]

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2. Acharya P, Mathur M. Hidradenitis suppurativa and smoking: A systematic review and meta-analysis. J Am Acad Dermatol. 2020;82(4):1006-1011. doi:10.1016/j.jaad.2019.10.044

Sustained-Release Bupropion

Bupropion (Wellbutrin) is a medication that is also used as a treatment for depression. Studies have shown that this medication is an effective treatment for smoking cessation.[1] This medication inhibits re-uptake of dopamine and norepinephrine neurotransmitters in the brain, which allows the effects of the neurotransmitters on mood and attention to last longer.[2] This mechanism is similar to the effects of smoking a cigarette on the brain, which can reduce some of the withdrawal symptoms that commonly occur with smoking cessation.[2] Sustained-release formulations of this medication are often prescribed.[1] Treatment with bupropion has been shown to be more effective than treatment with NRT.[1] Bupropion can also be used in combination with NRT, which can slightly improve rates of smoking abstinence after 1 year of treatment.[1]

As bupropion does not contain nicotine and is generally safe to continue long-term, it may be a preferable smoking cessation treatment for people with HS. Some studies have also found that bupropion may have some anti-inflammatory effects and can decrease levels of TNF-α, an inflammatory protein that is considered to be pathogenic in HS.[3-6] Bupropion may also be preferable in patients who are concurrently experiencing symptoms of depression, due to its use as an antidepressant.

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Varenicline

Varenicline (Champix) is a molecule that has partial activity at the same receptors in the brain that nicotine acts on.[1] This helps to reduce nicotine withdrawal and cravings by activating the same pathways of the brain that smoking a cigarette would activate. Varenicline may be slightly more effective than bupropion in the first few months of smoking cessation, but overall smoking abstinence rates are similar at about one year.[2] Combination treatment with NRT and/or bupropion is also an option and can help improve smoking abstinence rates.[3]

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Psychological Treatments for Smoking Cessation

Methods developed in psychology that are used to help people to quit smoking can be highly effective alone or in combination with medical treatments. Psychological treatments may include cognitive behavioural therapy, motivational interviewing, telephone or virtual support programs, and support groups.[1,2] This can help you to identify factors in your life that trigger you to smoke or make smoking cessation a challenge and can help you to set a series of realistic, achievable goals end goal is to quit or reduce smoking. Support groups can also give people a network of others who are going through the same challenges with smoking cessation and can help you to feel that you are not alone in your goal.

The availability of these programs may depend on your geographic location and which programs are covered by health insurance. The best step for accessing psychological support for smoking cessation is to ask your family physician if there are support programs that patients can be referred to in your area. It may also be helpful to discuss smoking cession with your dermatologist. Dermatologists are recognizing the benefits of counselling on smoking cessation to help their patients with HS and some pharmacies are taking the initiative to provide these services to patients who are referred by a dermatologist.

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Summary

Overall, smoking cessation is one of the best steps that you can take to manage your HS if you currently smoke. However, it can be difficult for many people to quit smoking due to nicotine dependence as well as other psychosocial factors in their lives. You should not be discouraged if you have tried to quit smoking in the past and have relapsed. There are many medical and psychological treatments that you can pursue that can help you to quit smoking. Many people have successfully quit smoking and have found this to be a positive step in improving their overall health.

CHAPTER 7

Written by: Leah Johnston, Susan Poelman

Medical Treatments for HS

Chapter Introduction

This chapter will discuss the various medical treatment options that are available for HS. Options include supplements (discussed in chapter 6), antiseptic washes, topical medications, oral medications, intralesional steroid injections, laser treatments and biologic medications. Benefits and potential side effects of each treatment will also be outlined. Surgical treatment options will be discussed in chapter 8. It is common for HS patients to require multiple different types of treatments before seeing improvement of their HS. There is no one 'gold standard' treatment for HS and each individual patient may see very different results with the same treatment. It is also common for treatments to take multiple weeks or months to start to work. The best treatments for each individual patient will depend on severity of your disease, other medical conditions that you have, and personal characteristics such as your age and biological sex. If you have other medical conditions that may be related to your HS, such as inflammatory bowel disease, arthritis, diabetes, PCOS, and other skin diseases, it is important to let your physician know, as some treatment options for HS can also be used as treatments for your other medical conditions.

Does my HS need treatment?

The decision of whether or not to undergo treatment for HS is a personal decision and will depend on the severity of your condition, its impact on your daily life, and your personal preferences. However, HS can worsen over time if left untreated and can progress from small papules and blind boils to larger abscesses and sinus tracts, which can be very painful and a source of daily discomfort for patients who have severe HS. In addition, evidence from numerous clinical trials has shown that patients with Hurley stage III disease often have poorer responses to treatment compared to patients with Hurley stage I or II. Topical treatments are often ineffective on their own for late stage II or stage III disease, so oral or injectable medications will often be necessary to achieve effective disease control. Even if treatments are successful and lead to remission of your HS, patients with Hurley stage II or III often are left with permanent scars and sinus tracts in areas where they previously had HS lesions. Scars can be both painful and a cosmetic concern, and can be difficult and expensive to treat. Surgery is often necessary to heal sinus tracts that develop in stage II and III. Therefore, if your HS is active, it is recommended that you start treatment as early as possible to prevent disease progression and complications.

Regardless of which treatment options you choose, it is advisable that you continue to take your medications as prescribed by your physician, even if your HS improves. Treatment options such as antiandrogens and biologics are most effective with long-term continuous use and it is common for patients to experience worsening of their disease if they discontinue taking them. If you are concerned about medication side effects, are not sure if your treatments are working, or would like to change medications, you should contact your physician so that they can help you make changes to your treatment plan.

As a patient, it is important that you are satisfied with your treatment plan and are actively involved in choosing treatment options with your physician. Studies have shown that patients are more likely to adhere to medical therapy and have successful treatment outcomes when they understand how the medication will help their disease, how long they will need to keep taking it, the time that it will take to see results, what results patients typically experience, and potential side effects. You should feel fully informed of each of these aspects of treatment before starting any medical treatment. Although early treatment of HS is important, it is not a life-threatening condition that requires urgent treatment and you may wish to take days or weeks to think about which treatment options you would like to pursue. You should not hesitate to contact your physician if you have additional questions before making a decision on your treatment plan. The goal of this chapter is to give an overview of common HS treatments and answer common questions that patients may have about these treatments.

Skin Cleansers

A variety of topical skin cleansers and antibacterial washes can be purchased both over the counter or prescribed by a physician to help manage HS. Although HS is not an infectious condition, reducing bacterial overgrowth surrounding HS lesions may help to reduce inflammation and prevent lesions from becoming infected. Products that can be used at home to manage HS include sodium sulfacetamide/sulfur, zinc pyrithione, chlorhexidine, and benzoyl peroxide.

Sodium sulfacetamide is often used to treat inflammatory skin conditions, including acne, and is often combined with sulfur in prescription topical preparations.[1,2] It has both antibacterial and keratolytic effects, which can help to prevent the build-up of dead skin cells and reduce inflammation surrounding hair follicles.[2] Side effects of this topical treatment can include skin irritation, dryness, staining of clothing, and odor. Many patients prefer to use this product as a foam that they can rinse off after applying to reduce strong odor with use. Sulfur soaps can also be purchased as over the counter treatments.

Zinc pyrithione is another topical treatment used in dermatology that has significant antibacterial, anti-inflammatory, and anti-androgen effects.[3] Zinc pyrithione is commonly available in over the counter or prescription anti-dandruff shampoos and soaps. It has been recommended that HS patients use a shampoo or soap containing zinc pyrithione to wash areas that are affected by HS, such as the armpits and groin.[3]

Chlorhexidine is an antibacterial wash that is commonly used in medical centers to clean the skin prior to surgical procedures. Chlorhexidine has been shown to be beneficial in managing HS and can be purchased over the counter or prescribed by a physician.[4]

Benzoyl peroxide is an antibacterial agent that is used as an acne treatment and it can be purchased over the counter or prescribed by a physician. Benzoyl peroxide also has keratolytic and sebostatic effects (reduction of oil production by sebaceous glands).[5] This treatment is available in different preparations, including gels and washes. Benzoyl peroxide may be useful in managing HS and can be combined with topical antibiotics such as clindamycin.[6-8]

Over the counter skin cleansers and topical treatments for HS that are available in Canada

Produit	Sulfur	Zinc Pyrithione	Chlorhexidine	Benzoyl Peroxide
Effects on HS	Antibacterial, antifungal and keratolytic	Antibacterial, anti-inflammatory and anti-androgen	Antibacterial	Antibacterial, keratolytic and sebostatic
Type of product	Bar soaps, ointments, shampoos, creams, masks	Bar soaps and shampoos	Wash	Gels, washes, creams, lotions
Example Products	 **Grisi Bio Sulfur Soap with Lanolin**  **De La Cruz 10% Sulfur Ointment:**  **Acnomel Adult Acne Cream (8% sulfur and 2% resorcinol)**	 **Vanicream Z-Bar (zinc pyrithione 2% soap)**  **Head and Shoulders Classic Clean Anti-Dandruff Shampoo (zinc pyrithione 1%)**	 **Hibiclens (chlorhexidine gluconate 4%)**	 **Clean & Clear Acne Spot Treatment, Persa-Gel 5% Benzoyl Peroxide**  **CeraVe Acne Foaming Cream Cleanser Fash Wash (4% Benzoyl Peroxide)**  **Oxy Emergency Acne Cleanser (5% benzoyl peroxide)**

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Topical Resorcinol

Resorcinol is a topical chemical peeling agent that has been used in dermatology for over 100 years and is included in chemical peels as well as over the counter acne medications in lower concentrations.[1] For HS, a higher concentration cream can be prescribed by your dermatologist.

A clinical study has shown that applying 15% topical resorcinol cream once daily for 12 weeks can be effective in reducing the number of inflammatory HS nodules and abscesses by over 80% in Hurley stage I and II.[2] Patients in the study also found resorcinol useful in reducing pain associated with HS lesions. Side effects include mild local skin irritation, dryness and peeling of the outer skin later, and mild reversible brown discoloration, but this medication is overall well tolerated and patient satisfaction ratings for this treatment have been high.[3]

Some dermatologists have suggested that this treatment could be beneficial for new HS flare-ups after the initial [3] months of treatment as it can reduce pain and duration of new nodules, so HS patients could keep it on hand in preparation for new flare-ups.[2,4] Resorcinol has been found to be most beneficial in reducing inflammatory nodules and abscesses and may be most effective at managing mild to moderate HS.[2,5] While resorcinol has not been demonstrated to reduce the number of sinus tracts, it may be beneficial in reducing the length and thickness of sinus tracts and may be a useful addition to a treatment plan for more severe HS.[5]

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Topical Antibiotics

The most common topical antibiotic used to treat HS is clindamycin. Clindamycin is commonly prescribed in solution form as 1% clindamycin phosphate and is applied to the skin every day, sometimes multiple times a day.[1] Topical clindamycin has been found to be effective in reducing the number of inflammatory nodules and abscesses in mild to moderate HS and may be equally effective compared to some oral antibiotics.[1,2]

This treatment is generally very well-tolerated by patients, with the most common side effect being mild skin irritation and stinging with application.[1] One issue with long-term use of this treatment is resistance of bacteria on the skin to this type of antibiotic, which may be reduced by concurrently using benzoyl peroxide.[3,4]

Fusidic acid is another prescription topical antibiotic that is available as an ointment and it is commonly used to treat bacterial skin infections. One clinical study has found it to be effective in treating Hurley stage I HS.[5] However, antibiotic resistance is a concern with this medication, which may make it a less ideal treatment for routine use.[6]

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Topical Retinoids

Topical retinoids are vitamin A-derived creams, gels, or ointments that are commonly prescribed as a treatment for acne, as they can reduce excess oil production and excess keratin from dead skin cells that commonly occurs with acne.[1] Topical retinoids have not been widely studied in HS, but some previous publications suggest that these medications may be of some benefit for mild HS and should be explored further as a treatment option.[2,3] One HS management guide has suggested that 0.3% adapalene may be useful for HS.[4] Common side effects of topical retinoids include skin irritation, dryness, peeling and increased sun sensitivity, but they are generally well tolerated and effective treatments based on widespread use in treating acne.[1] Topical retinoids are generally avoided during pregnancy as this medication can potentially be absorbed through the skin and oral retinoid medications are known to have significant risks of fetal birth defects.[5]

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Oral Contraceptive Pills

There are certain types of oral contraceptive pills (OCPs) that dermatologists routinely recommend to female HS patients who are of child-bearing age. OCPs contain synthetic hormones that mimic your body's natural estrogen and progesterone, which are hormones that regulate the menstrual cycle. Different types of synthetic progesterone are available in different birth control pills. For HS, it is preferable to take a birth control pill that contains drospirenone or cyproterone acetate as the type of synthetic progesterone, as these pills have anti-androgen activity and can reduce activation of hair follicles by androgens to help improve HS.[1-3] Oral contraceptive pills can also be used to treat acne and improve menstrual cycle regularity. It is common for women with HS to report pre-menstrual flare-ups of HS and this is thought to be due to declining levels of estrogen and progesterone prior to menstruation.[4] For women who do experience pre-menstrual flaring of their HS, it may be an option to take an extended birth control regimen, in which you take an OCP every day continuously for up to 84-126 days.[3] This will reduce your frequency of menstruation and may help to reduce the frequency of when you experience HS flares.

Side effects of oral contraceptive pills are typically outlined in instructions within OCP packaging. One concern that may arise with birth control pills is that they may put you at a slightly increased risk of developing a blood clot, which can become a medical emergency.[5-7] The overall risks of this occurring are very low, but can increase if you have other major risk factors for developing a blood clot including a family history of blood clots, recent surgery, immobilization, obesity and smoking. It is a good idea to quit smoking if you currently smoke prior to starting treatment with an oral contraceptive pill.

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Oral Anti-Androgen Medications

In addition to anti-androgen OCPs, there are other anti-androgen medications that are commonly prescribed by dermatologists to treat HS, including spironolactone (also called Aldactone) and finasteride.[1]

Spironolactone is also used as a blood pressure medication and it works throughout the body to block the activity of androgen hormones at their receptors, which reduces the activity of androgen hormones.[2] Spironolactone is also used to treat hormonal acne in women.[2] The typical dose range that is used to treat HS is 50-150 mg taken daily.[3-5] In a previous study of 20 women with HS, 17 patients saw improvement in their HS on spironolactone and 11 (55%) went into complete disease remission.[3]

Anti-androgen medications are commonly used in combination with an oral contraceptive pill in women, as anti-androgen medications can cause menstrual cycle irregularity.[3] It is also important to combine anti-androgen therapy with other contraceptive methods, as becoming pregnant while taking an anti-androgen medication can cause harm to a fetus, including feminization of a male fetus.[3] Other known side effects of spironolactone include breast sensitivity and enlargement, dizziness and high potassium levels in the blood.[3] However, many patients in clinical studies did not experience any side effects on spironolactone.[3] Overall, spironolactone is relatively well-tolerated, safe for long-term use and is recommended by dermatologists as a first-line treatment for HS in women.[3-5] Spironolactone is not typically used in male patients.[6]

Finasteride is another anti-androgen medication that has been studied in HS patients.[7] Finasteride can be used as a treatment for female and male pattern hair loss, hirsutism (excess hair growth in women) and prostate enlargement in men and works to block the conversion of androgens to their more active forms at the hair follicles.[7] Finasteride has been shown to be safe and effective for HS treatment in both females and males and has also been used successfully in pediatric patients.[7] Side effects of finasteride are similar to spironolactone and include breast enlargement and sensitivity, dizziness, headache, nausea, and menstrual irregularities.[7,8] However, this medication is generally well-tolerated with 80% of patients in a previous study reporting no side effects.[8]

Finasteride is also contraindicated in pregnancy due to feminization of the fetus, but like spironolactone, it does not cause long-term changes in fertility or reproductive hormones, so it can be prescribed to female patients who may want to become pregnant in the future.[7,9] In male patients, sexual dysfunction can occur with use of this medication but this side effect is reversible.[9] Overall, this medication is well tolerated and effective for treating HS and can be used as an alternative treatment option to spironolactone.

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Metformin

Metformin is an oral medication that is often prescribed to patients with diabetes or PCOS who have clinical signs and blood tests results showing insulin resistance. In type 2 diabetes, the body's cells become progressively less sensitive to insulin, causing the insulin-producing cells of the pancreas to initially make more insulin than usual. High insulin levels can increase production of androgen hormones, which can act at the hair follicle to worsen HS. Metformin works to improve sensitivity of the body's cells to insulin and in clinical trials, metformin has been shown to improve HS.[1,2] Side effects of metformin include nausea, stomach upset and diarrhea, but these symptoms improve after a few weeks of taking this medication and it is generally well-tolerated by patients.

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Oral Antibiotics

Although HS is not caused by an infection, oral antibiotics are commonly used to treat HS for people with mild to moderate HS that cannot be controlled with topical therapy alone. Antibiotics can also be used to manage flare-ups of severe HS. Certain antibiotics have anti-inflammatory effects which can reduce the number of inflammatory papules and nodules that develop with HS. Common oral antibiotics that are used to treat HS include minocycline, doxycycline, clindamycin with or without rifampicin, amoxicillin with clavulanic acid (for acute abscesses) and dapsone.[1,2] Typical antibiotic courses for HS last about [3] months.[1] Tetracycline antibiotics (minocycline and doxycycline) tend to be used for mild to moderate HS, while either clindamycin/rifampicin or tetracycline antibiotics may be equally effective for moderate to severe HS.[3]

Side effects of antibiotic treatment varies with each different medication but common side effects include stomach upset, nausea, vomiting, diarrhea and reduced effectiveness of oral

contraceptive pills.[1-3] Specific side effects with antibiotic treatment should be discussed by your physician or pharmacist prior to starting treatment. Some antibiotics, such as minocycline and doxycycline are not safe to take during pregnancy or for pediatric patients and should be avoided.

One challenge with this treatment is that HS improvement may not last long after a course of oral antibiotics.[4] In one study, the mean time of relapse after a 10-week course of clindamycin/ rifampicin was about 5 months after patients had experienced initial disease remission.[5] In addition, multiple extended courses of oral antibiotics carry the risk of antibiotic resistance, which can limit antibiotic treatments that can be used if you develop a bacterial infection in the future. Antibiotic treatment is gradually falling out of favour for treating non-infectious skin conditions such as acne and hidradenitis suppurativa, as new treatment options are becoming available.[4,6]

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Oral Retinoids

Oral retinoids are a class of medications that are derived from vitamin A and are commonly used to treat severe acne. The most common oral retinoid medication, isotretinoin (also known as Accutane), has mixed evidence from published research on whether or not it is useful in managing HS. Isotretinoin works to reduce the size and activity of the sebaceous glands (oil-producing glands) to prevent the build-up of keratin and bacterial in the hair follicles, which is the mechanism of how acne occurs.[1] Current clinical practice guidelines for dermatologists in North America recommend isotretinoin as a second or third-line option for treating HS, while European HS guidelines do not currently recommend isotretinoin as an HS treatment.[2,3]

Some previous studies have found isotretinoin to be beneficial as an HS treatment, particularly in young women with Hurley stage I or II HS, who also have concurrent, severe acne and patients with a history of pilonidal sinus/cysts.[4,5] Some patients have gone into partial or complete remission of HS [4,5] This improvement is thought to result from immunomodulatory effects of isotretinoin.[6] However, other studies have found that isotretinoin has not been effective for the majority of patients or may have even worsened the severity of HS.[5-10] The

mechanism of how isotretinoin may worsen HS is that the sebaceous glands in HS lesions are often smaller than expected in size, so further decreasing sebaceous gland size and activity may worsen HS.[10] This may explain why previous studies in patients with both acne and HS have found that while acne may improve significantly with isotretinoin, it may have no effect on HS in the same patient.[11]

Acitretin is another retinoid that has been studied in HS and has shown some evidence for improvement of HS.[12-15] In one clinical study, all 12 patients had improvement in their HS after a 9-12 month course of taking this medication daily and 9 patients experienced no recurrence of HS at 6 months post-treatment.[13] Some researchers believe that acitretin may be a more effective oral retinoid for treating HS, as patients who previously did not respond to isotretinoin treatment have had their HS improve on acitretin.[12]

Alitretinoin is a newer retinoid that has a similar mechanism of action to acitretin. One clinical study has found that 78.5% of patients had improvements in their HS.[16] Alitretinoin may be a preferable treatment in women of child-bearing age compared to acitretin due to having a shorter half-life, which is the time that the drug stays in the body.[16,17]

Oral retinoids are contraindicated in women who are planning a pregnancy in the near future as they can cause severe birth defects if taken during pregnancy. For isotretinoin and alitretinoin, female patients are advised to not become pregnant during treatment and 1 month after treatment has ended to allow time for the drug to clear from the body.[17,18] For acitretin, pregnancy may need to be avoided for up to 2-3 years following the end of treatment due to risks to the fetus.[13]

If you are interested in undergoing treatment with an oral retinoid, your dermatologist will discuss risks and benefits of treatment, recommended dosages, how long you will need to take your medication, when follow-up visits will occur, and any bloodwork monitoring that is required during treatment. For acne, treatment usually occurs over a period of [4-6] months. Common side effects of oral retinoids include dryness of the skin, eyes, lips and nose, nosebleeds, increased sun sensitivity, a temporary increase in hair shedding, and elevations in liver enzymes and blood lipids.[18] Taking doxycycline or minocycline along with an oral retinoid could cause severe headaches and worsening of vision, so it is recommended to stop taking these medications before you start the retinoid.[19]

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Intralesional corticosteroid injections

Corticosteroids can be injected directly into HS lesions to help reduce pain and the time it takes for an individual lesion to become inactive. Steroids can act to reduce local inflammation in HS nodules by suppressing production of pro-inflammatory proteins by immune cells.[1] This is often a very effective treatment for quick improvement of acute HS flare-ups.[1-3] The most commonly used steroid for these injections is triamcinolone acetonide (Kenalog), which is commonly used for skin and joint injections. Some dermatologists who specialize in treating HS will have schedules which allow HS patients to book urgent fit-in appointments to receive corticosteroid injections if a flare-up occurs.[4]

Treatments are usually recommended to be done at least 3-6 weeks apart with a limited amount of steroid injected at each session.[5] This helps to minimize the risk of systemic side effects occurring from injections. The overall risk of systemic effects is low if maximum dosages and recommended treatment frequencies are followed.

The most common side effects that can occur at injection sites are skin thinning/atrophy, hypopigmentation (lightening of the colour of the skin) and the appearance of telangiectasias, which are red, dilated blood vessels that are visible on the surface of the skin.[5]

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Botulinum Toxin Injections

Botulinum toxin (Botox) injections have been investigated to treat HS. Botox is a treatment that is FDA approved to treat hyperhidrosis (excessive sweating), especially of the armpits. Excessive sweating is more commonly reported by HS patients compared to the general population and many HS patients identify sweating as a trigger for HS flare-ups, so Botox injections may help to improve HS symptoms and overall quality of life.[1] Previous case reports and one small clinical trial found that Botox may be an effective treatment for HS, as it can reduce the number of inflammatory lesions and pain that HS patients experience.[1] Treatment sites for HS have included the armpits, underneath the breasts, the groin, and the gluteal region. No complications have been reported with this treatment in HS patients.

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Laser Hair Removal

Laser hair removal can often be an effective treatment option for HS. Hair follicles are currently understood to be the primary site of inflammation that leads to the formation of HS nodules and abscesses. Laser hair removal involves using wavelengths of light that selectively destroy hair follicles, reducing potential for inflammation. Randomized control trials using monthly long-pulse Nd:YAG laser hair removal treatments were successful in progressively improving HS disease severity, with patients giving high treatment satisfaction ratings at the end of the trials.[1-6] Discomfort during laser hair removal treatments is minimal and no recovery time is required, other than the guideline of keeping treated areas out of the sun for weeks following treatments. However, a significant barrier for many patients to accessing laser hair removal treatments is cost. Laser hair removal is not covered by many health insurance plans, although some insurance companies may allow you to submit claims from treatments if you have a health spending account on your insurance plan. Some dermatology clinics may give patients discounts due to having a medical condition that warrants this treatment, but even then, single treatment sessions may cost hundreds of dollars. Many expert physicians believe that laser hair removal treatments should be covered by health insurance and more advocacy for HS patients is needed in this area.[7] If you are able to afford paying out of pocket for laser hair removal, most dermatologists agree that it is a worthwhile treatment that can improve your HS. Laser hair removal may be more effective in patients with Hurley stage I or II HS, due to reduced scar tissue in affected areas, but researchers have also noted improvement in patients with Hurley stage III HS.[3]

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Biologics and Immunomodulatory Medications

Biologic medications are medications that block the actions of inflammatory proteins to reduce inflammation in the body. Biologic medications are used to treat multiple other inflammatory and autoimmune conditions, including inflammatory bowel disease, arthritis, psoriasis, and severe eczema. Biologic medications are progressively becoming available as biosimilar medications, which are generic versions of the same drug and have the same efficacy as brand name medications, but are less costly for insurance companies to pay for on drug plans.[1,2]

Humira (adalimumab) and its biosimilar medications are currently the only biologic medications that are FDA-approved for treatment of HS.[3,4] Humira is an injectable medication that is designed to block the actions of TNF-α, an inflammatory protein that has been found in higher levels in patients with HS. Large randomized control trials and studies at individual medical clinics have found Humira to be effective for treating moderate to severe HS.[3-8] Over 50% of patients with moderate to severe HS experienced significant improvements in reduction of inflammatory lesions, pain and overall quality of life.[5,8]

The most common side effects with biologic therapy are injection site reactions, but treatments are generally well-tolerated and can be done at home by patients.[9] Studies have determined that weekly injections are needed to achieve the best possible treatment response.[8]

A pooled analysis of the safety of Humira that included 30,000 patients from multiple different clinical trials has found that the incidence of serious adverse events, including infection and malignancy to be low.[10] This study looked at the number of years that patients had been taking Humira and investigated the number of reported serious events per year, which was presented as a statistic called 'person-years.'[10] In HS, the overall rate of infection was 2.8 per 100 person-years and the rate of malignancy was 0.5 per 100 person years.10 With these statistics, it is important to keep in mind that patients who are approved on biologic therapy tend to have more severe disease and may have a higher inflammatory disease burden, which may have put them at risk for developing an infection or malignancy regardless of whether or not they were on biologic therapy.

Other biologic medications that have successfully been used off-label to treat HS include infliximab, anakinra, ustekinumab, etanercept, and golimumab.[8] Some biologic medications that are used to treat psoriasis by blocking activity of the inflammatory protein IL-17 have been found to be effective in treating HS. These biologics are brodalumab, a biologic that blocks

receptors for IL-17, and secukinumab, which directly binds to IL-17A and prevents it from being active in inflammatory pathways.[11,12]

Clinical trials are currently ongoing for JAK1 inhibitors, which are a class of oral immunomodulatory medications, to determine if these medications are effective for treating HS.[13] Apremilast, an oral immunomodulatory medication that works as a phosphodiesterase 4 inhibitor, has also been effective for treating moderate HS in one clinical trial.[14] Prednisone, an oral steroid that can suppress immune system over-activation, is not often used alone to treat HS due to high relapse rates after prednisone is tapered.[15] However, some studies have found that low-dose prednisone may be beneficial in managing severe HS in combination with other treatments, such as biologic medications and may improve treatment responses.[15]

Reasons why someone may not be a good candidate for biologic and immunomodulatory medications include a history of severe active infections such as hepatitis B, hepatitis C, and HIV, moderate to severe heart failure, active malignancy or malignancy in the past 5 years, multiple sclerosis and some other neurologic conditions, and active tuberculosis infections.[9] It is common for patients to undergo screening for these conditions, including blood tests and other screening tests before receiving approval to start biologic treatment.[9] Another important consideration prior to biologic treatment is health insurance coverage. Biologic medications can cost thousands of dollars per year and may be unaffordable for patients without health insurance plans that cover prescription medication costs. Sometimes dermatologists can apply for “Compassionate Use” from the biologic company for these patients. Most insurance companies require that patients have tried other treatments, such as a 3-month course of oral antibiotics, before they will approve coverage of a biologic medication.

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Scar Treatments

It is common for people with HS to experience scarring and skin pigment changes after active HS lesions have resolved.[1] Although scars can fade over time, some persistent changes to the skin can remain long-term. Different types of scars can form with HS and this depends on age, genetics, the location of the body, size of the previous lesion, length of time that the lesion was present, and any local trauma to the skin including infection.

Many HS patients report concerns with both the cosmetic appearance of scars and pain/mobility restriction that may occur with build-up of scar tissue over time.[2,3] Although HS scars often occur in areas of the body that are typically covered by clothing, one research study found that people with scars in less visible areas can sometimes experience more distress from scars than people with scars in more visible areas of the body.[3,4] Some HS patients with scars describe activities such as swimming and intimacy to be uncomfortable for them due to feeling self-conscious about their scars.[2,3] Conversely, HS patients who have had successful treatments for scarring after disease remission have reported improved self-esteem and psychosocial well-being.[5] Treatment of scars can be a very important part of an HS management plan for some patients and if scars are negatively impacting your quality of life, you should discuss this important aspect of your care with your dermatologist.

The first step in scar treatment is optimizing the medical treatment of HS so that older lesions can heal and new lesions are less likely to form. Early and effective treatment will help to minimize the amount of scarring that results from HS. Unfortunately, scar treatments are often considered to be cosmetic treatments, so health insurance may not cover costs and if you are paying for treatments, you will want to ensure that any scar treatments you receive will be effective and provide long-lasting results.

Once your HS is well-controlled, you can discuss options for scar treatments with your dermatologist. Although there are many over the counter products available at cosmetic retail stores, most of these products have limited evidence supporting their efficacy and can be expensive. Dermatologists have specialized training in scar treatments and have an in-depth understanding of which treatments are most likely to be effective. It is advisable to have a consultation with a dermatologist prior to financially investing in a treatment plan to make sure that you will get the best possible improvement in your scars.

Treatment plans for HS scars depend upon the specific type of scar. Scars can be atrophic (depressed), hypertrophic (raised), or keloids (raised scars that extend beyond the initial lesion).[1,5] Both post-inflammatory hyperpigmentation (red/purple pigmentation) and hypopigmentation (lighter pigment than surrounding skin) can occur, depending on your skin type and any treatments that you've had in that area, such as intralesional steroid injections.

Specific treatment options for hyperpigmentation can include lightening creams, which often

contain hydroquinone, topical retinoids, chemical peels and lasers which specifically target pigment in the skin.[6] Hypopigmentation can occur more commonly in darker skin phototypes and treatments such as topical calcineurin inhibitors (pimecrolimus 1% cream), topical prostaglandin analogues, narrow band ultraviolet B phototherapy, and laser treatments have been used successfully to re-pigment areas of skin with pigment loss.[7]

For atrophic scars, injections of normal saline, dermal filler and laser treatments could help to lift tissues so that the scars appear less depressed compared to the surrounding skin.[8-11] Topical retinoids, such as adapalene, have been found to be useful in improving atrophic acne scars by stimulating production of collagen in the skin, which may also be beneficial in improving atrophic HS scars.[12,13]

Hypertrophic or keloid scars can be treated with intralesional steroid injections, 5-fluorouracil and laser treatments.[1,14-17] Two previous case studies in HS patients have found 5-aminolevulinic acid photodynamic therapy (5-ALA PDT) and fractionated CO2 laser treatments to be effective in treating raised scars.[5,17]

Other treatments that can be effective for different types of scars include silicone scar gels, microneedling and gently massaging scars with petroleum jelly.[1,18,19] These treatments can improve skin texture and reduce symptoms such as itch and discomfort.

A combination of different treatments may be needed to give the best possible improvement in your scars. It is important to have realistic expectations about treatment, as in most cases, scars will not completely resolve with treatment. However, scar treatments can significantly reduce scarring and can be a worthwhile investment to improve your quality of life.

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Treatments to Avoid for HS

Progesterone-Only Contraceptives

Research in other hormonally-related medical conditions including acne, female-pattern hair loss, and hirsutism has found an association between triggering or worsening of these conditions and progesterone-only methods of contraception.[1-3] Progesterone-only forms of contraception include hormonal IUDs (ie. Kyleena and Mirena), progestin oral contraceptive pills (OCPs) injections, and implants.[1] Some forms of progesterone can act similarly to androgen hormones and past studied suggest that this may worsen acne.[2] Although no formal studies have been done in HS, some dermatologists have observed an association between worsening of HS and use of progesterone-only contraceptives.[4]

Although combined hormonal oral contraceptive pills contain both estrogen and progesterone, combined OCPs tend to have less androgenic activity and can be prescribed to treat acne.[3] If you have HS and are interested in hormonal contraception, a combined OCP with anti-androgens such as drosperinone (ie. Yaz/Yasmin) or cyproterone acetate (ie. Diane-35) can potentially improve your HS.

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Microwave-Energy Sweat Gland Ablation

Current evidence supports that HS patients should avoid this treatment. Microwave-based energy treatment devices, such as miraDry, have been proposed to permanently treat hyperhidrosis (excessive sweating) by destroying apocrine and eccrine sweat glands below the skin in regions such as the armpits. Because of this, many experts thought that this could be a new advance in HS treatment. However, one small clinical trial of this treatment in HS patients have shown that this treatment worsened HS in the majority of patients, with patients showing worsening of disease exclusively in the armpit that was treated with miraDry and no significant changes in the untreated armpit.[1] There have also been case reports of new onset axillary HS developing after microwave ablation treatments in people who did not previously have HS.[2,3] Thus, microwave ablation treatments should be avoided by people who have HS or have a family history of HS.

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Finding the Best Treatment Plan

The best treatment plan for HS will depend upon the severity of your HS, other medical conditions that you have, lifestyle, geographic location and access to specialized medical services, costs of medications and if you have medical insurance that pays for prescription medications. As there is no one best treatment for HS and response to any particular treatment is variable, it is common for people with HS to have to try multiple different medications, surgical treatments, and lifestyle changes before they find the optimal plan to treat their HS. The best overall plan may include a combination of different treatments, as it is important to address hormonal, inflammatory, and environmental factors that are known to contribute to HS. In addition to medical treatments, surgical procedures, dietary interventions, lifestyle changes and smoking cessation (if applicable) are also important factors in managing HS. These topics will be discussed in detail in chapters 7, 8, 10, and 12.

CHAPTER 8

Written by: Leah Johnston, Susan Poelman, Ralph George

Surgical Treatment for HS

Chapter Introduction

If you have HS, your doctors might recommend that you undergo surgery. There are numerous approaches to surgery. Remember that even if you undergo surgery, it may not permanently cure your HS. You may have to undergo repeat surgeries. This is because HS is a chronic disease and may appear again and again. It can be in remission, but it can always surface during your life. Other variables may have to be considered in terms of determining your suitability for surgery. If you have a job, and are not able to have time off for at least a week, surgery may not be a good option for you. This is because you will need time off to be admitted for surgery, undergo the surgery, and recover from surgery. You may be exposed to other treatments in addition to surgery. Overall, the way that surgery is performed will depend on the area of your body that is affected by the disease and to what degree there is HS involvement in your skin. As a general rule, surgery is a challenge for doctors because they want to remove the unhealthy or diseased tissue in your body and keep the normal or healthy tissue. Surgeons are able to meet the challenge in most instances when they are treating patients with HS.

Suitability for surgery

Most patients with HS require combined medical and surgical therapies. The best candidates for surgery are patients with localized but severe disease. If the disease is limited to the axillae or groin, particularly with the presence of draining sinuses or scarring, surgery is very often a key part of treatment to ensure a better outcome. However, patients with multiple diffuse lesions with inflammation are better candidates for medical therapy.

Can I undergo surgery?

It helps if your overall health is good if you are planning to have surgery. When someone has more than one health condition, it may make it difficult for them to undergo surgery. People who have diabetes that is uncontrolled, for example, do not heal from surgery as quickly as people who do not have diabetes. Age is another factor to take into consideration in determining if someone is a good candidate for surgery. As people age, they likely have more health conditions, and that may make surgery a difficult course of treatment. If someone has poor circulation, it is something that surgeons take into account when making a decision to perform surgery. If you are a smoker, you will likely have poor circulation. That can lead to poor healing from surgery. You will be advised that it is preferable to stop smoking before surgery, and some surgeons may refuse to perform surgery on those who continue to smoke because they want the best outcome of a surgery. If you do not smoke after your surgery, it will help with the healing process. It is also better for your overall health, and probably for your HS, to stop smoking altogether. A surgeon will also want to know if you are prone to infection. Infections can develop after surgery if wounds do not heal properly. Doctors and nurses will take extra care to make sure that what they come into contact with is clean. That means washing hands, sterilizing equipment, and sterilizing surfaces. These steps are taken to make sure that healthcare providers protect against infection.

According to the Centers for Disease Control in the US, about 1% of the roughly 27 million operations performed annually in the US results in infection.

Fortunately, most of the infections that occur as a result of surgery are minor infections and are restricted to the skin around where the surgeon had made an incision or incisions. Keep in mind that serious infections can occur after an operation. It is estimated that serious infections that occur after surgery cause 8,000 deaths each year in the US.

Clinicians may offer you medical therapies aimed at reducing inflammation for optimal outcome of surgery in patients who have serious disease. Some of those therapies include antibiotics, hormonal treatments, or biologic agents.

Whether general or local anesthesia is used for your surgery depends on the extent of the surgery. Patients often experience greater fatigue after surgery if they have been exposed to general anesthesia, meaning that they are not awake during their operation. Local anesthesia, by contrast, is when just the area that is being surgically treated is frozen or numbed. You will be awake during surgery if local anesthesia is used. Because anesthesia is used, you will not feel the sensation of the surgical instruments even though you are awake. It is like when you go to the dentist, and your dentist fills a cavity. Your recovery from surgery is more rapid when local anesthesia is used instead of general anesthesia. If a patient is particularly anxious about surgery, a surgeon will likely choose to use general anesthesia so that he or she can perform the surgery more easily. This will also be better for you as a patient, if you tend to get anxious. This way you will not be awake during the surgery.

The types of surgery for HS:

Local destruction

Local destruction involves destroying individual lesions that are usually smaller and thinner. Local destruction involves cryosurgery, cryoinfusion, electrosurgery, laser therapy and photodynamic therapy. These surgeries aim to destroy the lesion and any contents in it. When a patient has larger lesions or extensive fibrosis, local destruction is not very effective. Other surgical approaches should be adopted.

Laser Treatment

Certain types of lasers work in a similar way and destroy the tissue. Using the carbon dioxide laser is a new approach to treating HS. It can be used on more extensive lesions, which can be vaporized with treatment. Experience shows that using the carbon dioxide laser and surgically removing a lesion followed by second-intention healing (leaving the wound to heal on its own) produces good outcomes and few complications.

Incision and drainage

This approach will usually involve the use of a local anesthetic, meaning that you will remain awake during the surgery. The area around the abscess is numbed. The physician will make a cut or incision into the abscess, so that the pus that is contained in the abscess will drain from it. Your surgeon might also take a sample of the pus for testing. When all the pus has been removed, the surgeon will use a saline solution to clean the void that is left by the removal of the abscess. A wound dressing will be placed to cover the opening that is left and will absorb any excess drainage. When an abscess is deep, a dressing that is antiseptic may be placed inside the wound to keep it open so that the wound can heal from the inside out. This is just a temporary measure that may be used in an emergency department setting or in your family physician’s office for temporary pain relief. Many HS experts do not agree with this approach for a long-term solution and favor more curative treatments since the rate of recurrence with this

technique has been shown close to 100%. A patient may find that he or she is left with a scar after this procedure.

Punch debridement

Punch debridement, which is also referred to as mini-unroofing, is suitable for the removal of acute, inflammatory lesions. Debridement means getting rid of or removing damaged, dead, or unhealthy tissues. If damaged, dead or unhealthy tissues remain, they do not allow blood to flow to the site and they also allow bacteria to flourish at the site. Punch debridement can be performed in a clinic, an office, or hospital emergency room. A doctor will use a 5- to 8-mm circular biopsy punch for this procedure. The biopsy punch is placed over your lesion, and your doctor twists the device to obtain an opening. The surgeon might decide to take a sample, or what is called a culture, from the lesion to make sure that it has no infection. Debridement may need to be more aggressive if there is a lot of fluid content with debris. Cotton swabs are used to wipe away any excess fluid. Petroleum jelly or Vaseline® is applied to the wound and gauze or a bandage is applied on top. Recurrences are frequent with this type of intervention.

Deroofing Surgery

One of the most common surgical approaches for HS is called “deroofing” or “unroofing.” Deroofing can be used to treat nodules, abscesses, and sinus tracts. This procedure can be performed in outpatient clinic settings and requires only local anesthetic, which involves pre-procedural injection of lidocaine. Essentially, the roof of each abscess, nodule, and sinus tract is removed using surgical scissors and a curettage probe is used to explore a lesion for side passages, which could lead to the formation of new lesions if left untreated. Inflammatory scar tissue from HS lesions is then removed using a curette, which prevents recurrence in treated areas. Alternatively, electrocautery or a carbon dioxide laser may be used instead of surgical scissors to remove HS lesions.

Following deroofing surgery, recovery time is minimal and many patients are able to return to work the next day or within a few days of the procedure. Wounds from deroofing surgery are most often left to heal by “secondary intention,” which means that no sutures will be used to close the wound and the wound will be left open to heal on its own. Studies have found that there is a lower recurrence rate of HS lesions that heal by secondary intention compared to HS lesions that are closed with sutures. Your surgeon will provide you with instructions on how to care for deroofing surgery wounds.

Deroofing surgery is a tissue-sparing technique that is highly effective for treating recurrent HS

lesions and sinus tracts. More than 80% of HS patients who undergo deroofing surgery do not experience a recurrence of their HS in the same location.1 When your HS is advanced and you have sinus tracts, surgery is almost always required to remove these tracts. Taking medications will not get rid of your sinus tracts.

A video on deroofing procedure may be found on the CHSF website at www.hsfoundation.ca.

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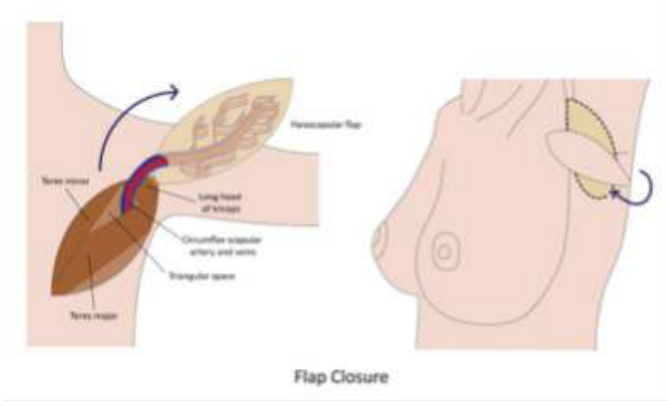
Excision



Patients who have recurrent disease that is categorized as Hurley Stage III are usually treated with surgical excision or surgical removal of their diseased tissue in combination with medical therapy. Surgery that involves wide local excision with skin grafting, skin flap transfer, and primary closure, where the edges of the wound are brought together, has been a common approach in managing advanced HS. Skin from another site on the body is transferred to cover the excision that is made to remove the diseased tissue. The affected area can be excised with a 1 to 2-mm margin, to ensure that the area is free of disease. The surgeon will also want to make sure that the excision is deep enough to get rid of deep, diseased tissues. Surgeons usually perform an excision in such a way so that they include some of your subcutaneous fat. It is a challenge when wide excision surgery is performed to provide sufficient coverage of the wound that is left behind.

When a surgeon wants to remove the sinus tracts in a patient with advanced disease, the surgeon will typically mark the areas intra-operatively with a small amount of methyl-violet solution. They color-code the zones where the sinus tracts are and make sure that they are fully removed during the procedure.

Skin flaps vs. skin grafts in surgery

There are skin flaps and skin grafts. In both cases, skin is taken from somewhere else, called the donor site, and placed in the surgical area, called the recipient site. With skin flaps, the tissue is never fully detached. It remains anchored on a blood supply. It is transferred to another site where the blood supply is reconnected. By contrast, with skin grafts, new blood vessels will form and “communicate” with new skin. This usually takes about three to four days. Whether they choose to use either flaps or grafts, surgeons are very careful to make sure that no major nerves are cut or affected and that other structures, such as muscles, bones, and tendons, are preserved.

Do the lesions come back?
Recurrence in patients with HS who undergo radical surgery varies considerably. Some of the factors that influence the recurrence rate include the location affected by disease, the type of surgery and severity of disease.

Your HS surgical team…general surgeons and plastic surgeons

Different types of surgeons perform surgery on HS patients. It may be a general surgeon or a plastic surgeon who performs your surgery. In some hospitals, colorectal or gynecological surgeons may also become involved in your care, depending on the part of your body affected by your HS. Regardless of the type of surgeon involved in your care, he or she will have a surgical plan. They will have a strategy of how they will operate and remove the diseased tissues that have been affected by HS.

A general surgeon is trained to diagnose, treat, and manage a variety of conditions that require surgery. A general surgeon provides operative and post-operative care to patients who might experience a trauma like a car accident or who are very ill and need life-saving surgery. Plastic surgeons focus on repairing, replacing, and reconstructing defects related to form and function of the body. For example, plastic surgeons perform breast reconstruction after a woman with breast cancer has undergone a mastectomy. Plastic surgeons have expert knowledge about things like skin flaps and how to make the surgical site appear as normal as possible. Either a general surgeon or a plastic surgeon can be equipped to perform surgery on a patient with HS. If you live in a very populated area, there will likely be general and plastic surgeons available. If you live in a less populated place, you will likely have fewer choices of who will be performing your surgery. You may have to travel for your surgery if you live in a rural area.

When possible, surgeons try to take steps to minimize the appearance of a scar and preserve range of motion, particularly in the areas of the axillae or groin.

A concern of many patients who undergo surgery is that they will be left with a scar that is very visible. When possible, surgeons try to take steps to minimize the appearance of a scar and preserve range of motion, particularly in the areas of the axillae or groin. Surgery that is minimally invasive is very popular amongst patients because it leaves very little, if any, scar.

Recovering from your surgery

You will probably experience pain after your surgery for several days. That is a very normal feeling and will subside depending on your type of surgery. If pain persists for two weeks or more, that might indicate that there is something wrong. It might be wise to call your surgeon

if the pain continues beyond two weeks after your surgery.

Some complications that follow surgery can be detected before you are discharged from hospital or clinic. Other complications, however, may only develop once you are already at home, recovering from surgery. An example of a complication that might develop after you have been discharged is a blood clot. Infection is also another type of complication that can develop once you are at home recovering. Typically, infections occur within the first 30 days after surgery if they do occur. You are probably not going to get an infection if you have been at home for more than 30 days and things have been healing well.

Think of this time as being good to yourself and compassionate and allowing your body to heal.

Depending on the site of your surgery, you may experience decreased mobility immediately following surgery. You may have to limit your mobility to allow the surgical site to heal properly. You will be able to gradually increase your mobility after two to four weeks. Try not to become frustrated with the fact that you have limited movement. Think of this time as being good to yourself and compassionate and allowing your body to heal.

Phone if you are unsure…

If you have concerns following your surgery, it is probably better to have a "low threshold for suspicion," meaning you should place a phone call to your surgeon if something appears or feels irregular at the surgical site. Your concern may be able to be dealt with over the phone without having to make a visit to be examined.

What you can do after surgery…

If you are given instructions about what to do after surgery, make sure you do the best you can to follow those instructions. You will probably be told to keep a wound clean to avoid the development of infection. It is also important that you follow a proper and healthy diet and avoid smoking. Your body is trying to repair itself after surgery and heal. It helps for you to have enough protein intake to allow your body to do this. It is also a good idea to consume foods that fight inflammation. Remember that inflammation is part of the body's immune response. Many vegetables and fruits fight inflammation. Some of the vegetables include broccoli, asparagus, and carrots. Some of the fruits include blueberries, blackberries, strawberries, and pomegranates. It is also important that you drink a lot of water to flush out your system and keep your body hydrated. In this delicate period of time when you are recovering from surgery, remember how important it is to avoid smoking. You should also avoid or limit alcohol intake. You want to make sure that you have healthy blood flow to allow the surgical site to heal. **This**

If you are given instructions about what to do after surgery, make sure you do the best you can to follow those instructions.

is an opportunity for you to take steps to be good to your body. You might find you will be as good as new -- or perhaps even better -- after surgery and your recovery.

CHAPTER 9

Written by: Rochelle Tonkin, Susan Poelman

Pain Management

Chapter Introduction

Pain management is integral to the treatment plan for HS patients and will vary based on the individual needs of each patient. Patients who have HS initially develop papules and pustules and then later develop nodules, cysts and abscesses that fill up with pus. Patients report experiencing a lot of pain and/or tenderness because of these lesions, particularly when the disease is active. That pain may make it hard to do daily things like clean the house, let alone participating in sports or other exercise. Many patients with HS, for example, are unable to work due to their illness because of the pain they experience.

If you have a new lesion developing that is very painful and debilitating for your daily life, you should contact your primary care provider or dermatologist. They may be able to provide immediate relief, such as injecting corticosteroids intralesionally into a nodule or an abscess. If you cannot reach your own family doctor or dermatologist to treat the painful lesion, visit your nearest emergency department. It is preferable that a health professional remove the boil, rather than lancing it, because it will greatly minimize the threat of infection and recurrence.

HS flares can cause acute pain that can be quite distressing. As HS is a chronic condition for many, over time pain can become a chronic issue as well. Chronic pain is defined as pain that lasts longer than expected for typical healing which is considered to be longer than three months.[1] As discussed throughout this book, appropriate treatment, wound care and other management strategies all contribute to treating the underlying HS disease which is the first step to reducing the burden of pain. However, HS tends to have unpredictable flares and pain may be challenging to manage at times. Therefore, it is important to find supportive healthcare providers that can help you manage your pain effectively and safely. The goal with chronic pain management is not necessarily that you be 100 per cent pain-free. Instead, the goal is offering a decent quality of life, managing pain at a tolerable level, and enhancing day-to-day functioning. These pain management strategies have been found particularly helpful for HS patients and recommendations will vary according to your individual needs and will be followed by pharmacologic pain medication and adjunctive topical therapies.

Non-Pharmacologic Pain Management

Non-pharmacologic pain management is recommended as the primary approach in chronic pain.

Mindfulness/Meditation

You will find that the pain may be worse at some periods in your life more than others. Finding ways to cope with your pain and HS overall is important for your mental and physical health. You can consider exploring things like mindfulness and meditation. Mindfulness has become a popular term in today's culture. Mindfulness means that you acknowledge your difficulties and challenges in life and how you respond to the difficulties. Mindfulness encourages being in the present and not dwelling on the past or worrying about the future. It refers to acting with awareness. Mindfulness can be helpful for patients who have dermatological conditions like psoriasis, acne, or HS. Patients with psoriasis or acne or HS may have social anxiety, as well as fear of negative evaluation related to their skin conditions. As a result, they will avoid social situations because of their skin conditions and their emotions associated with their conditions. A study published in the British Journal of Dermatology in 2016 of 120 adult dermatology patients found those patients who had increased levels of mindfulness experienced decreased psychosocial distress.[2] Patients with psoriasis who received mindfulness-based therapy as well as usual treatment reported better quality of life and less severity of their psoriasis, according to research published in Psychology, Health, and Medicine in 2015.[3]

Meditation usually involves sitting and breathing deeply. The goal is to quiet and clear your mind of negative thoughts. You may feel silly meditating at first, but like anything else, if you stick with it, you will find it can change how you view and experience your symptoms like pain. Prioritizing time to clear your mind can also be accomplished via other activities such as yoga, walking, running, or whichever activity works similarly for you.

Evidence-Based Psychological Therapies: Cognitive Behavioural Therapy (CBT) and Acceptance and Commitment Therapy (ACT)

The psychological impacts of chronic pain in HS, should be addressed in collaboration with your dermatologist, family physician, and/or mental health experts. This should be integrated with medical management of pain for maximal benefits. Evidence-based psychological therapies that can be applied to chronic pain in HS include CBT and ACT. Changing the way you think can take lots of time and practice.

For chronic pain, CBT is a well-known and effective first-line therapy that can be implemented in conjunction with pain medications or alone.[4] CBT, is a way to help cope with pain by changing how you think, which in turn affects how you feel.[5] CBT is often used to help patients think in a healthier and more balanced way.[5] The goal is to replace negative thoughts with healthier thoughts to reduce stress and pain.[5] Changing the way you think about pain helps your body and mind respond better when you have pain.[5]

Another technique derived from CBT is called ACT. ACT emphasizes learning to accept your negative feelings through psychological flexibility guided by one's goals in order to cope with pain.[6] This technique can help with understanding what influences our behaviour.[6] This technique teaches you to base your choices and actions on your personal values, rather than on negative feelings.[5]

Healthy thinking can eliminate discouraging thoughts that create barriers to daily functioning as well as towards being physically active.[5] Physical activity in turn, can help with pain.[5] There are added benefits to physical activity in HS as discussed in Chapter 11.

Medications

Topical Therapies

Topical therapies can be used for acute or mild chronic pain in HS and can be added in addition to other pain management therapies. Topical non-steroidal anti-inflammatory drugs (NSAIDs), lidocaine and menthol are recommended for reducing pain associated with HS lesions.[7] Topical therapies are typically well tolerated. Application of topical medications should be avoided areas of skin breakdown to reduce the possibility of skin irritation and systemic absorption.

Oral Medications

Acetaminophen and oral NSAIDs such as Ibuprofen or naproxen can be used as first-line therapy for HS-related pain.[7]

Neuromodulatory medications can help treat neuropathic (nerve)-type pain associated with HS. Gabapentin and pregabalin are anticonvulsant medications that have been shown to be effective for itching and neuropathic pain in HS.[7] Serotonin-norepinephrine reuptake inhibitors such as duloxetine and tricyclic antidepressants such as nortriptyline are typically used to treat depression and anxiety, and are also beneficial for HS.

Tramadol is the first-line opioid for acute pain only. Tramadol has a lower risk of side effects than typical opioids.[7] It is important to note that opioids can be associated with abuse of the medication and possible adverse side effects. When taking an opioid pain medication, over time you may build up a tolerance to that medication. As a result, the pain medication may become less effective. Studies have demonstrated that opioids do not offer better pain relief than non-opioid medications, particularly for chronic pain.[8]

Alternative Therapies: Cannabinoids

Some HS patients choose to use cannabis for their HS. The evidence to support the use of cannabinoids to treat pain is varied. A recent review of multiple studies has shown a reduction in chronic pain with the use of cannabis (37%) vs. placebo (31%).[9] In dermatologic conditions, cannabinoids have been shown to reduce itching, which can be bothersome in HS.[10] Studies have shown that the majority of HS patients were cannabis users prior to developing HS symptoms.[11] Therefore, it is proposed as a possible triggering factor for HS similar to tobacco, a well-known trigger.[11] This requires further study to determine if cannabis is a possible trigger for HS. There are risks associated with using cannabis, even for medical purposes. These possible risks include chronic cough, cannabis hyperemesis syndrome (paradoxical vomiting caused by using cannabis), arteritis (arterial inflammation that can lead to heart and systemic disease), and

various psychiatric disorders (commonly anxiety and depression).[12] We recommend that you ask your family doctor for more information about prescription cannabis for your HS, which is available in Canada.

Intralesional Corticosteroid Injections

Your doctor may suggest injecting cortisone where you have active disease and inflamed lesions on your body.[13] Cortisone is a steroid which acts as an anti-inflammatory agent. The goal is to provide relief from pain and swelling with intralesional cortisone injections. Some patients have a lot of success with this therapy. A recent paper demonstrated intralesional injections of corticosteroids into inflammatory lesions provided a major decrease in pain just one day after injection.[14] If the injections prove effective in treating your lesions, they will probably consider injecting cortisone again if you develop new nodules or abscesses. See Chapter 6 for more information about this treatment option.

Surgery

If you have solitary nodules, small excisions (removal of the lesion) can be performed, and this procedure usually provides some temporary pain relief. Incision and drainage may be done for some abscesses in an emergency department, family physician's office, or dermatologist's office setting to temporarily relieve pressure and pain by removing the pus. This is not a long-term solution as it does not remove the lesion, and many HS experts favor more curative treatments such as deroofing surgery since the rate of recurrence with this technique has been shown close to 100% (see chapter 7).

If you undergo surgical treatment, you will probably experience pain after your surgery for several days. That is a very normal feeling and will subside depending on your type of surgery. If pain persists for two weeks or more, that might indicate that there is something wrong. It might be wise to call your surgeon or physician if the pain continues beyond two weeks after your surgery.

Dressings

Dressings with extra cushioning to relieve pressure and with silver imbedded in them have been shown to reduce pain in lesions that have become painful wounds (see chapter 12).

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CHAPTER 10

Written by: Rochelle Tonkin, Marc Bourcier, Susan Poelman

Skin and Wound Care

Chapter Introduction

Skin and wound care are a very important part of HS management and good wound care can significantly improve the quality of life for HS patients. Flares can be unpredictable, and many patients find it challenging to deal with acute and/or chronic, recurrent, draining wounds which can result in physical, psychological, financial, and emotional distress. Appropriate wound care aims to promote wound healing, prevent infection; and to help manage pain, comfort, odor and clothing staining. You may search online and find remedies for HS being offered. It is probably not a wise decision to try these remedies without first checking with your family physician or dermatologist to get their opinion about the remedy and whether it's a good idea. We aim to address the challenges of confusing online information, vast selection, cost and accessibility of products and remedies by providing this information to help you find what works for you.

Basic Skin Care

Basic skin care measures can be very effective in prevention of flares, as well as in combination with good wound care and your specific topical or oral treatments.

- Keep skin cool. It is okay to apply heat for quick pain relief, however, overheating and sweating can cause HS flares. During warm weather, try stay cool by seeking shade or staying in indoor spaces.
- Reduce friction. Some people find that their HS flares with tight or form-fitting clothing. Opting for looser-fit clothing can help.
- Reduce sweating/moisture. When it is difficult to limit sweating, you can try absorbent powders, and antiperspirant (topical aluminum chloride). However, some antiperspirants are too harsh for skin affected by HS. If you need help reducing sweating, talk with your dermatologist.
- Maintain good hygiene. Daily bathing with antiseptic washes can be used to keep the skin clean, as well as reduce pain and discomfort. (See “Wound Care” section for more about this).
- Decrease odor. Regularly change dressings (sometimes multiple times per day may be required). A clean washcloth soaked in diluted white vinegar can be applied before you dress a wound.[1,2]

Wound Care

Wound care plays an important role in treating HS, as HS can cause slow healing or non-healing wounds. If you need wound care, you will be taught how to do this at home. These supplies can be purchased from your local pharmacy, wound care clinic or medical supply store. In the beginning, some patients need to change their dressings several times a day.[3] If you need extra help, wound care clinics and community home care providers can perform dressing changes and debridement (removing unhealthy tissue to allow for better wound healing).

Antiseptics

Antiseptic washes, such as silver and iodine, suppress potential bacteria that contribute to immune triggers of HS, decrease bacterial pathogen colonization seen in HS, and decrease risk of infection.[4] This can be used regularly during non-flares, flares, and post-surgery. Chlorhexidine washes are also commonly used as antiseptics.

Dressings

Dressings absorb discharge or pus from ulcers that leak or seep. What you use to care for your wounds can vary. Your dermatologist will consider where you have wounds, the amount of leakage coming from the wounds, the type and severity of the wound, cost, availability, and your preferences. Applying dressings is an integral part of good wound care which aids in protecting the healing skin from trauma and infection.

Dressing choices will vary based on the type of lesion (ie. superficial, tunnelling sinus tracts, odorous, amount of fluid production, pain, post-operative) and are detailed in Table 1. Some of the materials include foams, hydrofibers, and calcium alginates. Silver-impregnated foam is considered the most optimal HS dressing because it contains nearly all the desired characteristics. However, silver-impregnated foam is expensive and sometimes difficult to access; therefore, alternative more cost-effective dressings may be considered first (***Figure 1***).[5] You also want to find a dressing that properly fits a location like the underarm, for example, for it to be effective. A dressing that is atraumatic avoids damage to the skin and reduces pain when there are dressing changes. If you have had a boil or abscess removed with surgery, proper wound care is vital in the healing process. You can ask your dermatologist or wound care dressing supplier to recommend a specific dressing brand that fits the desired criteria, as brands will vary based on region and availability.

Table 1. Understanding dressing choices based on lesion type. (Adapted from the American Academy of Dermatology, Kazemi et. al, and Braunberger et. al.)[3,5,6]

Lesion Type	Recommended dressing	Rationale
Superficial lesion	Plain, absorptive dressings	Keep it simple
Acute nodule (painful with minimal or no drainage)	Nonadherent dressings (such as hydrocolloid, hydrofiber, alginate, or foam dressings).	Foam dressings provide an extra layer of cushion to reduce pain from accidental pressure or impact.

Cavity or tunnelling sinus tract	Dressings need to be sufficient to fill the cavity and absorb fluids. • Acute/Flare: Superabsorbent and absorbent dressings. • Chronic: Dress based on amount of drainage. Hydrocolloid dressings can facilitate autolytic debridement if needed.	Flared sinus tracts are associated with heavy drainage and pain. In chronic sinus tracts, there is a need to reestablish balance by activating phases of wound healing, addressing the amount of moisture present, and reducing the necrotic burden.
Odorous lesion	Avoid hydrocolloid dressing.	To avoid trapping smell in dressing.
High drainage nodule or sinus tract	**1st line:** regular gauze, infant diaper, sanitary napkin, adult brief or abdominal pad. **2nd line:** hydrofibre with silver and calcium alginate with silver. **3rd line:** silver-impregnated foam.	Able to absorb high drainage output. For continuous high output drainage control, consider silver-impregnated foam dressings due to absorbent nature of foam, and antimicrobial benefits of silver.
Painful nodule or ulcer	Silver-impregnated foam	Atraumatic adhesive leads to less painful application and removal.
Post-operative wound after HS surgery	Silver-impregnated foam	Antimicrobial; absorbs debris and bacteria into foam, thereby promoting more efficient healing.
Slow-healing or non-healing wound	Superabsorbent or absorbent dressings, foams, silicone adherent dressings, hydrofiber dressings, alginate dressings, or advanced bioactive dressings, such as the platelet-rich plasma and hyaluronic scaffold dressing. If a wound fails to heal, hyperbaric oxygen therapy (HBOT) may be an option.	HBOT is better known for treating scuba divers who come up from a dive too quickly. Patients receive HBOT by going into a special chamber. The oxygen level inside the chamber is higher than normal. Getting more oxygen into your blood may help heal non-healing wounds.

The everyday care of HS abscesses or boils is very individualized and depends on availability and cost of the dressings. The types of dressings you choose can be tailored to fit within your budget (***Figure 1***). The variety of dressings can be accessed through your local pharmacy, medical supply store, or online stores such as Amazon. Finding top-tier dressings can be tough to navigate on your own, so we have provided you with a few examples (***Table 2***). Inquire with your insurance plan to see if you have coverage, as this can help mitigate the financial burden associated with expensive dressings. Alternatively, consider the lower-tier, more readily available and affordable dressings such as pads, gauze, sanitary napkins, and absorbent briefs that can be found at the pharmacy.

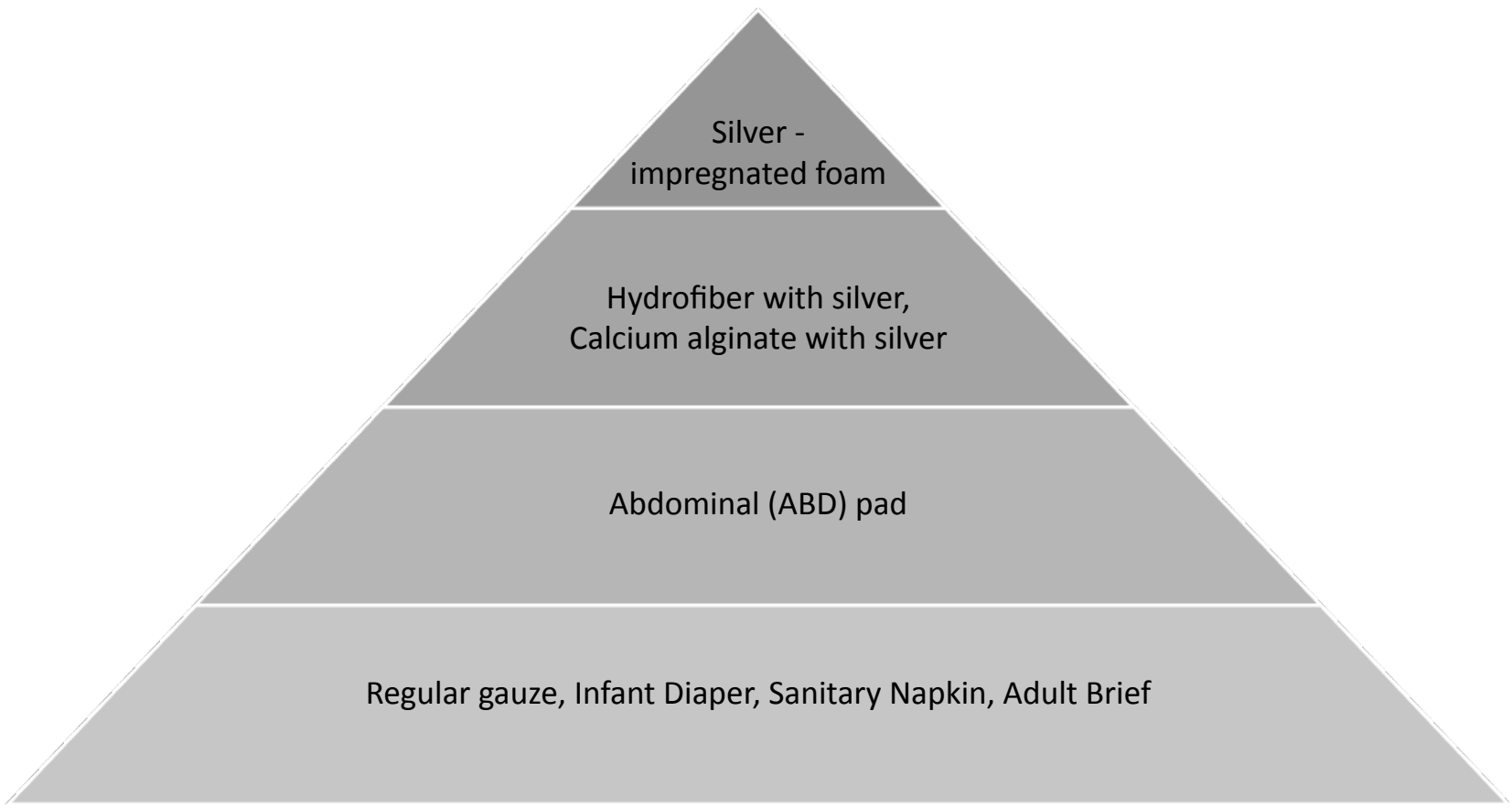
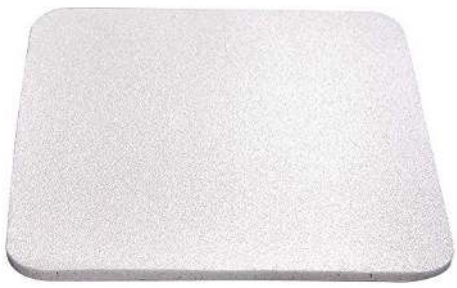
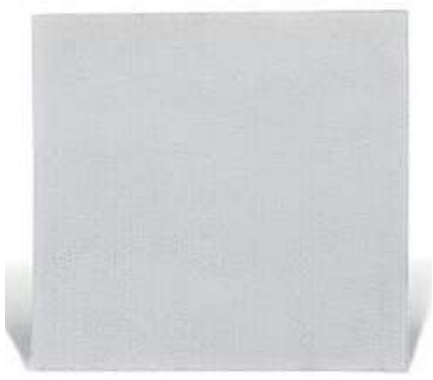


Figure 1. Pyramid of HS wound care management based on cost and ease of accessibility. Bottom tiers include the most cost-effective and easy-to-access dressings available at local pharmacies and supermarkets; and range to top tiers including the most effective, but expensive, dressings that are accessible through a wound care center or surgical supply store.

Table 2. Top-tier dressings: what they look like, product examples, and where to find them.

Top-Tier Dressing		Product Examples	Amazon link
Silver impregnated foam		Areza Silver Foam Dressing	https://www.amazon.ca/Areza-Silver-Dressing-Sterile-dressings/dp/B08W8G1N2M/ref=sr_1_130?dchild=1&keywords=silver+foam+dressing&qid=1630961779&sr=8-130
Hydrofibre with silver		ConvaTec Aquacel Ag Hydrofiber Wound Dressing With Silver	https://www.amazon.ca/ConvaTec-Aquacel-Hydrofiber-Dressing-Sterile/dp/B078YJ7TF7/ref=sr_1_1?dchild=1&keywords=silver+hydrofiber+dressing&qid=1630961965&sr=8-1
Calcium alginate with silver		MedHeal by Medvance Silver Calcium Alginate Ag Sterile Highly Absorbent Antibacterial Dressing	https://www.amazon.ca/Alginate-Absorbent-Antibacterial-dressings-MedvanceTM/dp/B07WZ1V753/ref=sr_1_47?dchild=1&keywords=silver+foam+dressing&qid=1630961563&sr=8-47

Expected Healing and Possible Complications

With normal wound healing, the wound surface area should be reduced by 20% every 2 weeks.[6] This is not the case for chronic HS wounds, but is more typical of post-surgical wounds after stimulation of healthy healing. Watch out for signs of slow healing or non-healing wounds, infection, overgrowth of the new tissue at the base of the wound called hypergranulation, death of normal tissue called necrosis (appears black) and infection (symptoms include warmth, swelling, pain, and spreading redness; with or without pus and fever/chills). If any of these signs arise, see your dermatologist or if urgent concern of infection, go to the emergency department where they will assess further. Rarely, severe complications can occur such as: risk of developing a skin cancer called squamous cell carcinoma, secondary amyloidosis developing in scars, anemia of chronic disease, local swelling of affected areas called lymphedema, openings to surrounding structures such as the vagina or rectum called fistulas, and joint pain.[2]

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Basic At-Home Remedies

- Treat a painful lump at home with heat. If you have a painful, deep lump, doing one of the following can bring quick relief:
  - Place a warm tea bag on the lump. To do this, boil water. Once the water boils, place a teabag in a cup and pour the boiling water over the tea bag. Let the tea bag steep in the hot water for a minute. Then remove the warm tea bag and place it on the HS. Keep the tea bag on that spot for 10 minutes.
  - Apply a warm compress. To make a warm compress, place a clean washcloth under hot water. Wring out the excess water. Then apply the warm compress to the HS for 10 minutes.
    [https://www.aad.org/public/diseases/a-z/hidradenitis-suppurativa-self-care]

CHAPTER 11

Written by: Leah Johnston, Yulia Lytvyn, Raed Alhusayen

Mental Health and HS

Chapter Introduction

Once you have received a diagnosis of HS, you may feel relieved to finally have an answer about what has been going on with your skin. Patients have reported that one of the most difficult parts of their HS journey was having to visit multiple different doctors over a number of years before finally receiving an accurate diagnosis.[1] Once you have a formal diagnosis, you can pursue treatment options that may help improve your condition. However, not all patients may feel a sense of relief after receiving a diagnosis of HS. As HS tends to be a chronic condition, many patients may feel overwhelmed at the thought of having a medical condition that does not have a permanent cure. The initial months of becoming diagnosed with HS can be overwhelming while you are learning about HS and the many different treatment options for it. All of this new information, along with reading about experiences of patients who are severely affected by HS, can be distressing and cause significant anxiety about having a diagnosis of HS.

It is common to need to try multiple treatments to manage HS and even effective treatments can take many weeks or months to start working.[1] Some treatments for HS can be expensive and may not be covered by health insurance plans, which can add to the burden of having HS.[1] Once after finding an effective medication regimen, some people may still experience HS flare-ups. This can be a source of significant anxiety and at times, you may feel as though you are not in control of your own body.

In addition, some people with HS can feel alone in their experiences with this condition. HS is not a well-known condition in the general population and it tends to affect areas of the body that are often covered by clothing, so some people with HS find it can be difficult to discuss this condition with others in their lives. Other factors that can impact one's mental health while living with HS include feeling self-conscious about the visual appearance of their HS and having to manage symptoms such as odour and drainage.[2] Some people with more severe HS may have to deal with being unable to work due to significant pain and needing to spend a significant amount of time on daily wound care.[1,2] A combination of these factors can lead to increased rates of depression and anxiety in people who have HS. One study found that 17% of HS patients met diagnostic criteria for depression and 5% met diagnostic criteria for generalized anxiety.[3]

This chapter will discuss ways to improve your mental health while managing HS, how to recognize symptoms of anxiety and depression, and how to seek help for these conditions. With proper treatment for your HS, flare-ups can eventually improve and become less frequent. You can still have a happy and fulfilling life despite having HS.

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Finding a Treatment Plan and a Physician to Help Treat your HS

One of the most important steps that you can take to manage your mental health is to have a plan in place to treat your HS. One challenge for someone who has HS can be feeling as though they have no control over their condition, and starting treatment can help. Some people see their HS improve significantly with treatment and some are fortunate enough to achieve symptom remission. Once your condition is more tightly controlled, it is less likely to interfere with your daily life. HS patients with more mild disease often fear that their HS will get worse over time and seeking treatment early could help to prevent progression of HS.[1]

In addition, finding a dermatologist who is supportive and understanding of the challenges that people with HS often face can help make having HS feel much more manageable. They can help you choose treatment options that are most likely to be effective based on your medical history and stage of HS. They can also help put you at ease by answering your questions and setting up a plan to manage acute flare-ups of your HS. Your dermatologist can also help support you if you are struggling with your mental health and they can refer you to resources that other people with HS may have found helpful.

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Discussing your Condition with Family and Friends

Dealing with any chronic illness can take a toll on your mental health and it can be helpful to share what you are going through with people who are close to you. This can help you to feel that you are less alone and can help people in your life to be more understanding if you haven't been able to make it to family or social events because of dealing with HS symptoms. Discussing HS may be difficult, especially if your loved ones have never heard of the condition

before. However, since HS can be genetic, you may find out that some of your family members may also have symptoms of HS. It may be beneficial to find online websites and resources to share with your loved ones so that they can learn more about HS. Websites that are useful for learning more about HS are listed in chapter 14.

Learning More About HS

Learning more about HS can help you to feel more prepared to handle challenges that can occur with HS and provide you with a better understanding of the treatment options and supports available to help manage your condition. Although you may have received some information about HS from your physician, many patients choose to learn more about HS using online resources. However, it is important to take breaks and set limits for yourself if you find that you have been spending too much time reading about HS and are feeling distressed while you are browsing through HS-related content. The goal of learning about your condition should be to help you manage your condition, rather than making you feel fearful and anxious about the future. Focus on reading content that provides you with factual information on managing HS and helps you to feel more in control of your condition. It is equally important to consider the source of any information that you read about online. While you can learn a lot from other patients' experiences on online blogs and discussion forums, it is important to consider that HS treatment recommendations on these platforms may or may not be supported by scientific evidence. If you want more information about treatment options, it may be best to read websites and articles that state that they have been written and reviewed by a physician or team of other healthcare professionals.

Join a Support Group

There are many support groups available for just about any topic, concern or health condition, including HS. It can help you realize you are not alone and there are other people with similar concerns. One you realize that you are not alone and are in a safe and supportive environment, you will be more comfortable sharing your story with the group that is nonjudgmental and encouraging. Additionally, support groups offer a lot of practical tips and resources, as members share their strategies for managing HS that may be helpful to you. There are both virtual and in-person support groups that you can attend. Your dermatologist may be able to recommend local support groups for people with HS.

Invest Time in Activities

that You Are Passionate About

Although being diagnosed with a chronic condition can feel overwhelming and may consume much of your time and mental energy in the initial weeks and months, it is important to remember that your diagnosis is just one part of your life. Becoming invested in projects at work, engaging in hobbies, spending time with your friends and family can be essential to providing structure in your life during this difficult time and taking your mind off of the stress that you are dealing with from having HS. Regular exercise can help you to manage stress and help you to stay as healthy as possible.

Mindfulness

Taking a mindfulness-based approach to managing your mental health can help you to improve your mental health and overall sense of well-being. Mindfulness involves becoming more aware of your thoughts and emotions and learning to accept them as they come, while not allowing these thoughts to take over the present moment.[1] Mindfulness approaches have been studied in patients with chronic illnesses and studies have shown that this strategy can result in improvements in measures of both mental and physical health.[2] Resources for practicing mindfulness in your daily life are widely available as free online websites and videos. Evidence for mindfulness in dermatology is discussed in chapter 9.

1. What is Mindfulness? Mindful website. July 8, 2020. Accessed August 7th, 2021. https://www.mindful.org/what-is-mindfulness/
2. Merkes M. Mindfulness-based stress reduction for people with chronic diseases. Aust J Prim Health. 2010;16(3):200-210. doi:10.1071/PY09063

Taking Time for Self-Reflection

Self-reflection is another important aspect of mental health. If you are having a bad day and are feeling anxious, hopeless, or overwhelmed, you should take time to acknowledge those feelings rather than avoiding or minimizing them, and then reflect on why you feel a certain way. Identifying your feelings and understanding why you have them can help identify specific things in your life that are not going well and this knowledge can help you set goals for things in your life that you would like to change or work towards.

Grounding Exercises to Help Reduce Anxiety

Managing anxiety in the moment can help you refocus on the present and move forward with your daily tasks and activities. Groundings exercises help redirect your thoughts away from the cause of anxiety and focus on your here-and-now. There are a number of groundings exercises to choose from, pick one that works best for you. It takes practice and is most effective if started early before anxiety symptoms get out of control. One common exercise is called box/square breathing. It allows you to focus on your breathing instead of the current stress you may be experiencing. First, breathe in for 4 seconds, then hold the breath for 4 seconds. Breathe out

for 4 seconds and hold the breath out for 4 seconds. Continue repeating the exercise from the beginning as needed. Another grounding exercise focuses on your body awareness and physical sensations. In step 1, relax your shoulders and unclench your jaw. In step 2, place your right palm on the forehead and take deep breaths through your belly. Step 3, place right palm on your heart and continue to focus on your breathing. In step 4, place the left hand on your belly and feel it expand and relax. Finally, a 5-4-3-2-1 exercise may help you distract from anxious thoughts and focus on current sensations. To do this exercise, take a break in your day to think and focus on 5 things you can see now, 4 things you can feel now, 3 things you can hear now, 2 things you can smell now and 1 thing you can taste now.

Anxiety and Depression

Although many people have days where they feel anxious, worried, depressed, or fatigued, anxiety and depression are lasting changes in mood that can interfere with your day-to-day functioning.

Depression can be diagnosed when you experience at least 5 out of 9 of the following symptoms, most of the time for a period of 2 weeks or longer:[1]

1) Depressed mood
2) Loss of interest or pleasure in daily activities
3) Significant weight loss or gain (>5% of body weight in one month)
4) Insomnia or hypersomnia
5) Fatigue
6) Agitation or slowing of movements
7) Feelings of worthlessness or inappropriate guilt
8) Decreased concentration
9) Thoughts of death or suicide.

If you are having thoughts of suicide or self-harm, please seek urgent medical attention or phone your local mental health crisis line for support.

Generalized anxiety disorder can be diagnosed when you experience excessive anxiety and worry that is difficult to control for most days for at least 6 months, and your anxiety is related to a variety of different events and settings. Experiencing 3 out of the following 6 symptoms is needed to meet diagnostic criteria for anxiety:[2]

1) Restlessness or feeling on edge
2) Fatigue
3) Difficulty concentrating
4) Irritability
5) Muscle tension
6) Insomnia (difficulty falling or staying asleep).

If you are experiencing symptoms of either depression or anxiety, it is a good idea to visit your family physician. They will discuss your symptoms with you and will likely want to order blood

tests and other evaluations to rule out any medical conditions that could be contributing to your symptoms. They can provide you with a formal diagnosis of a mental health condition, discuss treatment options and resources that they can refer you to, including other mental health professionals.

Treatments for anxiety and depression can include medications and/or psychological interventions such as cognitive behavioural therapy (CBT), which was discussed in chapter 9. It can take a few weeks to start to see improvement of your mental health condition with treatment, but many people see significant benefits of treatment after the first few weeks or months. Some medications can have side effects such as GI upset, so it is important to ask your doctor about the common side effects before you start taking them.

1. Malhi GS, Mann JJ. Depression. Lancet. 2018;392(10161):2299-2312. doi:10.1016/S0140-6736(18)31948-2
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Conclusion

Although receiving a diagnosis of HS can be overwhelming, there are many options to help manage this condition and it is possible for your HS to get significantly better with treatment. It is important to remember that it is not your fault that you have this condition, as many people with HS have a genetic predisposition towards developing the condition. It can be helpful for your mental health to focus on the future and things you can do to improve your condition, such as finding a physician who specializes in treating HS, beginning treatment, and making lifestyle changes if needed. If you are experiencing symptoms of depression or anxiety and need additional support with your mental health, you should reach out to your family physician, dermatologist or a mental healthcare professional.

CHAPTER 12

Written by: Leah Johnston, Yulia Lytvyn, Raed Alhusayen

Pregnancy and HS

Chapter Introduction

Becoming pregnant is a significant life milestone for many and is wonderful news if you want to start a family! Pregnancy is a time where you will need closer monitoring for your overall health and it is recommended that you have regular appointments with a maternity care physician throughout your pregnancy. A family physician or obstetrician can provide your maternity care and they will help you to monitor any chronic conditions you have and screen for common concerns that can occur in pregnancy. If you have active HS, it is important to let your physicians know, as this is something that could impact your quality of life during pregnancy. You should also let your dermatologist know that you are pregnant, as this will impact which treatments you can receive for your HS. Most women with HS can safely undergo pregnancy and have a normal vaginal delivery, but the hormonal changes that occur during and after pregnancy may impact your HS. This chapter will discuss current evidence for how pregnancy can impact HS, treatment options that are safe in pregnancy, and HS challenges that could arise around delivery or in the months after delivery.

Is HS Affected by Pregnancy?

Previous studies have shown variability in reports of how HS is impacted by pregnancy.[1-5] It is possible for HS to improve, worsen, or remain unchanged in severity during pregnancy. Hormonal changes occur during pregnancy, which could contribute to either an improvement or a worsening of HS.[2] Pregnancy can have both pro-inflammatory and anti-inflammatory effects on the body.[5] Gaining weight during pregnancy may be a source of friction and stopping HS medications during pregnancy might aggravate HS in some cases. It can be difficult to predict how HS will be impacted by pregnancy in any individual patient. Thus, it may be beneficial to have a dermatologist be involved in your care while you are pregnant, as they can help you to come up with a treatment plan to manage your HS if you do have flare-ups in pregnancy. It is also important to let your obstetrician know about your HS diagnosis, so that they can help you manage your HS and anticipate any challenges that may arise during the pregnancy, at delivery or in the post-partum period.

Treatment Options for HS that Are Safe in Pregnancy

When doctors decide whether or not a medication is safe to use during pregnancy, they will look at the FDA pregnancy category of a medication. Pregnancy category A medications are medications that have had well-controlled clinical trials in humans that have found no evidence of maternal or fetal risks.[1] Pregnancy category B medications are medications that have not had reported adverse outcomes reported in pregnancy in humans, but have not had large randomized control trials done to support their safety.[1] Medications that may have the potential for risks during pregnancy based on animal studies but benefits may outweigh risks, or medications that have not been studied in animals or humans are labelled as pregnancy category C medications.[1] Both Pregnancy category A and B are medication categories that are considered to be safe for use during pregnancy. Some pregnancy category C medications are also considered safe in pregnancy. Most medications that physicians consider safe for use in pregnancy are classified as pregnancy category B rather than category A, as ethical considerations make it unfavorable to do clinical trials during pregnancy.

Category D medications are medications that have shown evidence for fetal risks in human pregnancies but benefits may outweigh risks of treatment in some cases.[1] Category X are medications that are contraindicated in pregnancy due to significant fetal risks.[1]

Medications for HS that are safe during pregnancy include topical clindamycin, topical benzoyl peroxide, oral clindamycin, oral metronidazole, metformin, zinc (up to 50 mg per day), adalimumab and infliximab.[1,6,7] Laser hair removal, intralesional corticosteroid injections and local in-office surgical procedures, such as de-roofing surgery, are safe to do during

pregnancy.[1] For pain management, acetaminophen (Tylenol) is generally the preferred first-line treatment during pregnancy.[1] Oral rifampin and dapsone are classified as pregnancy category C medications and may be considered for use in pregnancy in severe cases, but may have some associated fetal risks and are less preferred in pregnancy compared to other treatments.[1,6]

Medications that generally should be avoided in pregnancy include oral tetracycline antibiotics (doxycycline and minocycline), finasteride, spironolactone, oral contraceptive pills, and topical and oral retinoids.[1,6] There is insufficient data to determine whether or not topical resorcinol is safe for use during pregnancy, so some experts recommend avoiding treatment with this medication in pregnancy.[1] NSAIDs, including ibuprofen, should generally be avoided in pregnancy.[8] If you are trying to become pregnant, you should discuss this with your dermatologist and discontinue taking these medications.

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Other Considerations for Management of HS during Pregnancy

Routine obstetrical care will screen for common health concerns that can occur in pregnancy. Studies have shown that women with HS may be at an increased risk for developing some of these complications.[1-3]

A common concern that many pregnant patients experience is anemia during pregnancy. People who have HS may be at increased risks of developing anemia in pregnancy.[1,2] Anemia can be a risk factor for complications such as low birth weight and preterm birth, so it is important that you complete all recommended bloodwork with your obstetrical care physician to screen for anemia and other complications.[4] Iron deficiency anemia can be effectively treated with oral iron supplementation or in severe cases, IV infusions of iron.[5]

Gestational diabetes is another common condition that can occur during pregnancy. Studies have shown that this condition may be more common in women who have HS.[1,2] All pregnant women are recommended to undergo routine screening tests for gestational diabetes at 24-

28 weeks of pregnancy, which often includes an oral glucose tolerance test.[6] If the screening oral glucose tolerance test is positive, you may be recommended to undergo further testing or start treatment for gestational diabetes. If you have diabetes in pregnancy, it is important to monitor your blood glucose and ensure that your blood glucose is well-controlled, as diabetes in pregnancy can increase risks of pregnancy complications.

Women with HS may also be at risk for gestational hypertension (high blood pressure), which is a common pregnancy concern that occurs due to impaired blood flow through the placenta, which leads to an increase in blood pressure throughout the body.[1-3,7] Women with pre-existing high blood pressure are at an increased risk for this complication. Gestational hypertension can lead to a condition called pre-eclampsia, which carries risks of serious health complications for both pregnant women and fetuses. This condition occurs in about 3.8% of pregnancies, but one study found that pre-eclampsia occurred in 6.6% of pregnancies in women with HS.[2]

Signs and symptoms of pre-eclampsia include headache, changes in vision including seeing flashing lights, nausea, vomiting, pain in the right upper abdomen, decreased frequency of urination, and swelling of the legs and feet.[7] In severe cases, pre-eclampsia can turn in to eclampsia, which is diagnosed if you have a seizure. Because of the devastating and life-threatening risks of this condition, obstetrical care physicians typically monitor blood pressure at every appointment and if your blood pressure appears to be borderline high, they may ask you to monitor your blood pressure at home. If your blood pressure is higher than 140/90 or you start to develop symptoms of pre-eclampsia, you should contact your care provider immediately or go to a designated emergency maternity care triage hospital for further assessment.[7] Your medical team will monitor your blood pressure and fetal activity and order standard blood and urine tests for pre-eclampsia. Pre-eclampsia can be managed with blood pressure medications, but ultimately, the best treatment to prevent complications is delivery.[8] If you have signs of pre-eclampsia, your obstetrician will likely advise you to undergo an induction of labor.

While it is important to be aware of common pregnancy complications, it is also essential to remember that these complications occur in a minority of pregnancies. Although slightly increased risks of complications have been found in women who have HS, individual pregnancy complications occurred in a minority of women with HS.[2,3] Obstetricians are well versed in detecting and managing pregnancy complications, which is why it essential to attend regularly scheduled visits with an obstetrician during your pregnancy.

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HS and Delivery

One concern that women with HS may have, particularly if they have HS in the inner thighs, vulvar or anogenital areas, is whether or not their HS could impact their ability to undergo a vaginal delivery. As HS lesions tend to be sterile and not infected, risks of transmitting infection to a newborn during the pregnancy or delivery is likely to be low, but may occur if there is a secondary bacterial infection.[1,2] Routine pregnancy care involves doing a cotton swab of the vagina, perineum and rectum for group B streptococcus (GBS) bacteria at around 35-37 weeks of pregnancy.[3] If the GBS swab is positive, treatment with IV antibiotics will be given at the time of delivery to prevent an infection of your newborn baby if you have a vaginal delivery.

In some severe cases, some obstetricians may recommend a caesarean section over a vaginal delivery.[4,5] Two research studies have shown that women with HS are about 5% more likely to undergo a caesarean section (32% and 37%) compared to women without HS (27% and 32%).[6,7]

One risk of caesarean section is that for patients who have HS lesions on the lower abdomen, this may impact placement of caesarean incision and depending on where the lesions are, some obstetricians may choose to make the incision higher on the abdomen than the typical incision site.[5] HS may also impact healing of the incision site after delivery and there have been some reports of new HS lesions developing at the site of the incision.[5,8,9]

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HS in the Postpartum Period

The postpartum period can be an exciting and challenging time for many women as they recover from childbirth and begin parenthood. Hormonal and immune changes occur after pregnancy, as your body shifts back to its non-pregnant state. Because of these changes, one research study found that 66% of women reported postpartum flaring of HS.[1] As the postpartum period is often a busy time, it may be a good idea to discuss a plan with your dermatologist prior to delivery about how you will manage HS flares in the postpartum period. If you plan to breastfeed, this may limit some treatment options, but most treatments that are used to treat HS during pregnancy can also be safely used in the postpartum period.

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Breastfeeding and HS

One concern that women who have HS underneath the breasts may have is whether or not they are able to breastfeed after delivery. HS typically will not impact your ability to breastfeed, though pain may be a concern for some women.[1] If you have HS underneath the breasts and are planning to breastfeed, it is recommended that you undergo treatment prior to delivery if you have active lesions. Treatments may include topical antibiotics, oral antibiotics that are safe for pregnancy and breastfeeding, and intralesional corticosteroid injections.[1]

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Difficulty Becoming Pregnant

Some women may have difficulties with fertility and it can be a struggle for them to become pregnant. It may be your biology or your partner's, or a combination of factors that is making it difficult to become pregnant. A condition that can impact fertility and is more common in women with HS is polycystic ovarian syndrome (PCOS). Signs and symptoms of this condition are discussed in chapter 5. If you have PCOS and are struggling to become pregnant, there are many treatment options, including medications, lifestyle changes and reproductive technologies that can increase chances of becoming pregnant. If you have been trying to become pregnant for over a year with no success, it may be beneficial to consult your family physician or fertility specialist for support with becoming pregnant.

Conclusion

Although there may be challenges that occur during pregnancy if you have HS, it is possible to have a healthy pregnancy with HS. If becoming pregnant is an important part of your life goals and family planning, you should not let having HS deter you from becoming pregnant. With support from your dermatologist and your obstetrical care provider, HS flare-ups can be effectively managed and any complications that arise can be prevented or treated.

CHAPTER 13

Written by: Leah Johnston, Abrahim Abduelmula, Raed Alhusayen

HS in Children and Adolescents

Chapter Introduction

Adolescence is a complex and challenging time in any individual's life. It is a time in which you are going through many physical changes. Girls get their periods and start to develop breasts while boys' voices deepen and boys develop facial hair. Imagine adding to the usual changes that happen in puberty, that you notice that you are developing cysts and boils on different parts of your body. Many teens that experience HS are told that they have bad acne when they seek counselling from a health professional. This phenomenon, of HS appearing after puberty and often being mistaken for acne, contributes to the common delay in accurate diagnosis that many patients with HS experience.

HS in Children and Adolescents

Because HS typically appears after puberty, it is rarely seen in younger children and is not well-studied in younger children. There is some thought that if it appears in young children, it is a sign of precocious puberty, which is when a child's body starts to change into that of an adult earlier than when it normally should. Healthcare providers regard puberty that begins before age eight in girls and before age nine in boys as precocious puberty. Research shows that less than 2% of children develop HS before the age of 11.[1]

A study published in the Journal of the American Academy of Dermatology found that having a family history for HS was much more common in people who developed HS early on in life.[2,3] The study authors defined having HS early on in life as developing HS before age 13.

When children present with HS, it should be explained to them that this is a disease for which there is no cure, but that it can be managed so that they can live a full life. Children and their parents should be educated about the condition. Chances are that they have not heard of the condition. Healthcare providers will try with children who have HS, just as they do with adults who have HS, to stop the disease from getting worse. They will try to reduce pain, decrease inflammation and scarring, and by stopping the disease from getting worse, they will delay and hopefully prevent the need for surgery.

Treating Children and Adolescents with HS

Specific guidelines for treatments of HS in children and preteens are limited, as most clinical research studies for HS have been done with only adult patients. As a result, they are often treated for HS with the same therapies used in adults. These treatments are discussed in Chapter 7.

Topical antibiotics like clindamycin may be used in mild HS. Children with mild HS may also be treated with antiseptic washes such as 5% or 10% benzoyl peroxide cleansers. Regular use of antiseptic body wash does provide some relief in some patients and can help reduce odor. Topical resorcinol has also been successfully used in children and adolescents with HS.[4]

When a topical treatment does not work in a child or when a child's HS is moderate, that is having a few cysts or having a few cysts in multiple areas, a child can be given an antibiotic to be taken by mouth. Doctors often choose doxycycline, which is a tetracycline antibiotic, to treat adolescents as it has the lowest risk of side effects within the tetracycline class.[3,5,6] Tetracycline antibiotics are not recommended for children under the age of 8, as it can cause discoloration of the teeth and slowed growth of bones in this age group.[5,6] Oral clindamycin with rifampicin, erythromycin, metronidazole, and ertapenem are antibiotics that can also be used to treat HS in children.[3,4]

Finasteride, which is an oral anti-androgen medication, can be given to female patients with moderate HS.[7,8] This medication has been used in patients as early as age 6 and may be especially beneficial in cases of early onset puberty and signs of PCOS.[7,8] This medication can be effectively used in the long-term, though it is contraindicated in pregnancy, so female adolescent patients must be counselled on contraception. Finasteride has been used in adolescent male patients with HS, however, there are some concerns about unknown effects on male fertility and sexual function in this age group.[7-9] Spironolactone can also be used in female pediatric patients with HS.[7]

Oral retinoids such as isotretinoin may be useful in teenagers who also have acne, but as discussed in chapter 7, there has mixed evidence for their effectiveness in treating HS.

Surgical procedures, such as de-roofing, are also an option for the management of HS in children and can be performed for not just severe HS, but even in mild or moderate cases. One advantage of de-roofing surgery is that it is an in-office procedure that can be done in one clinic visit and requires only local anesthetic. Minimal recovery time is needed after this procedure, making it a favorable option to avoid missing large amounts of time from school.

Biologics drugs have shown good results in controlling HS and have also been given to children with advanced HS. Humira (adalimumab) has been approved by the FDA for use in children aged 12 and older with moderate to severe HS.[3] Clinical trials of other biologic medications for HS, specifically for use in the pediatric population, are currently being developed.

Botulinum toxin (Botox) injections have also been successfully used to control HS in children.[10]

Laser treatments are also an option to manage HS. Although laser hair removal can be expensive, it may be worth the expense to prevent future scarring and progression of HS. Laser treatments, such as CO2 lasers, can also be used to treat HS lesions.[11]

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What to Do if Your Child or Teenager has HS

Early recognition or diagnosis of HS in adolescence is vital to make sure the disease does not progress and become worse. If you think that your child may have HS, it is important to seek medical attention early and consider requesting a referral to a dermatologist. HS can lead to permanent scarring and chronic pain if not adequately managed and starting treatment early may help to prevent future complications. Early treatment will also reduce the potential of the disease to cause psychological harm and will help minimize the impact of their condition on their overall quality of life.

It is beneficial to follow any recommendations given by your physician and to advise your child to avoid things that could make their HS worse. Shaving should be avoided in areas where a child has an HS flare because the shaving can be a source of mechanical irritation. If your child is self-conscious about body hair, laser hair removal is an option that can also reduce the severity of HS. Clothing that increases friction and irritation of the skin can make their HS worse and it may be best to avoid wearing clothing items that are tight-fitting and allow skin-to-skin rubbing. Warm baths and compresses can also help to manage active flare-ups.

Psychological and Social Impact of HS in Adolescents

HS can be bothersome for someone at any stage of life. Throughout adolescence, there are many changes that are going on in your body, with hormonal changes and puberty. It is usually a period where you are very self-conscious about the changes that are taking place in your body. You do not want to stand out from the crowd. It is likely that more than ever that you want to fit in with your friends and other kids at school.

A study in the International Journal of Adolescent Medicine and Health shows that even teenagers who have acne, a condition that is common in teenagers, have low self-esteem, reduced quality of life, and high levels of social anxiety.

Adolescence is a time when boys and girls may experience their first romantic or intimate relationship. Teenagers with HS may choose to avoid social situations that lend themselves to romantic experiences like school dances or proms because of feelings of shame or embarrassment due to their HS. Many teens may struggle when it comes to dressing with their HS. Teens that have part-time jobs or play sports that require particular uniforms may struggle if these uniforms irritate their skin or make their HS visible to others. If not well-controlled, HS may limit participation in sports and other activities due to the pain of HS flare-ups.

Bullying, teasing, and making fun of others is something that is, unfortunately, common in adolescence. With the pervasiveness of the Internet and social media, there is also a potential risk of cyberbullying. Teenagers can be victims of hurtful comments and rumors online. They can also be threatened or have hurtful photos of them posted online on social media groups and chats channels like Facebook. Because of peer pressure and wanting to fit in, and possibly being fearful of bullying and cyberbullying, it is understandable that a teenager with HS does not reveal the condition to classmates and friends.

Support for Adolescents with HS

It may be beneficial for teenagers with HS to find support groups with other teenagers who have HS. This will provide them with a group of peers who they may feel comfortable with sharing their concerns about having HS at school, in their social lives, and at their part-time jobs. A good place to start is for teens to ask their healthcare provider about local support groups. Another step may be to look online at social media websites. They may find support just by reading comments and posts from others who have HS who say they are teens. However, it is important to be mindful of internet safety and to be cautious when revealing information that may be personally identifying.

It is important to have a good support system in place when coping with HS in teenagers. A new HS diagnosis can be a very stressful time in a teenager's life and having the right resources and supports in place can lead to the best results!

CHAPTER 14

Written by: Leah Johnston, Susan Poelman

Resources

This chapter provides an overview of resources that physicians and patients have found to be a factual source of information on HS and advice for how to manage this condition.

HS Online.ca (www.hsonline.ca)

This Canadian website supplies medical information about HS. It features personal stories of patients with HS and the challenges they have faced, and discusses ways to control your HS such as wearing comfortable, cotton clothing. There are also many tips including some on wound care and what you can do to cope with stress, as well as information about the benefits of maintaining a healthy body mass index.

Canadian Hidradenitis Suppurativa Foundation (www.hsfoundation.ca/en/home)

The Canadian Hidradenitis Suppurativa Foundation (CHSF) aims to increase awareness about HS and associated health conditions, support research on HS, encourage collaboration amongst physicians to improve the health of HS patients, work with other international foundations to expand research, enhance education, improve patient care, and assist patients with challenges they experience with having HS.

Hidradenitis Suppurativa Foundation, Inc. (www.hs-foundation.org)

The Hidradenitis Suppurativa Foundation, Inc., based in the US, is devoted to enhancing the quality of life and quality of care for patients and families affected by HS. The foundation promotes international research amongst scientists and doctors, with a goal to develop and deliver treatment that is effective for HS.

HealthCentral Hidradenitis Suppurativa Guide (https://www.healthcentral.com/collection/hidradenitis-suppurativa-guide)

HealthCentral is a website that has collections of articles written on a variety of different medical conditions, including HS. Published articles contain advice from expert dermatologists and are a great resource for learning about HS. Some notable articles include “Self-Care Guide for Your HS” (https://www.healthcentral.com/experience/hs-self-care-tips-from-experts) and “Let’s Talk About Treatments for Hidradenitis Suppurativa” (https://www.healthcentral.com/condition/hidradenitis-suppurativa-treatments).

HealthCentral is also useful as a resource for your loved ones to learn more about HS and contains articles written by HS patients to help others understand the challenges faced by people who have HS.

HS Aware (www.hsaware.com)

HS Aware is an online community dedicated to people with HS. The website features personal stories and experiences from HS patients and encourages patients to speak about their experiences with HS on the HS Aware Facebook page (www.facebook.com/IAMHSaware) and on the HS Aware Twitter account (@IAMHSAware). In June 2016, during HS Awareness Week, representatives from HS Aware travelled to Ottawa, Canada, and met with several Members of Parliament in Canada to bring attention to HS and its effect on patients.

European Hidradenitis Suppurativa Foundation (www.EHSF.eu)

The EHSF promotes research into HS and promotes training of doctors to improve the management of patients with HS.

The Hidradenitis Suppurativa Trust (www.hstrust.org)

The Hidradenitis Suppurativa Trust is a charity based in the United Kingdom. It is dedicated to growing awareness, understanding and support for HS. It aims to enhance knowledge about HS amongst the general public as well as the medical profession. The charity launched an awareness campaign which introduced the blue HS ribbon. The charity aims to have the purple ribbon become a recognized symbol of HS awareness throughout the United Kingdom.

Patient HS Denmark (www.Hidrosadenitis.dk)

Patient HS Denmark is a Danish patient association supporting patients with HS living in Denmark. Its members aim to increase knowledge of HS, ensure better diagnosis, focus on more effective treatment, gain acceptance of HS in society, and support and inform patientsand relatives.

Akne-inversa.org (www.Akne-inversa.org)

This is an association supporting patients in Germany who have HS. It aims to promote exchange amongst HS patients for them to find appropriate care for their HS. The website offers tips on how to prepare patients with HS for their next visit with their doctor and discusses topics such as nutrition for HS patients and recovery after surgery for HS.

National Organization for Rare Disorders (www.rarediseases.org/rare-diseases/hidradenitis-suppurativa/)

NORD is a US-based patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. It is committed to the identification, treatment, and cure of rare disorders through education, advocacy, research, and patient services.

No BS about HS (www.nobsabouths.com)

A US-based website sponsored by the pharmaceutical company AbbVie Inc. (maker of Humira®) which provides information about what HS is, the symptoms, treatment options, and what it is like to live with HS. It also provides links to various support groups.

Symposium on Hidradenitis Suppurativa Advances (SHSA) (https://www.hs-foundation.org/events)

The Canadian Hidradenitis Suppurativa Foundation (CHSF) and The Hidradenitis Suppurativa Foundation (HSF) sponsor a yearly conference for physicians, healthcare workers, students, people living with HS and their friends and family members to attend. This conference discusses the latest advances in HS research with panel discussions and presentations from leading experts in the field. The 6th annual SHSA event was held virtually in September 2021.