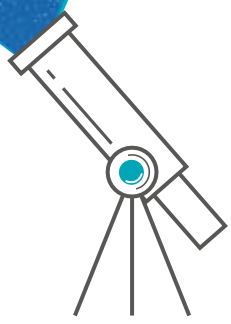
STRATEGIC HEALTH INITIATIVE
TO DETERMINE THE STANDARD OF CARE

FOR PATIENTS WITH HIDRADENITIS SUPPURATIVA



HERCULES
INICIATIVA ESTRATÉGICA EN HIDRADENITIS SUPURATIVA

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HÉRCULES
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Contents

Prologue

"I spoke with a 20-year-old girl with hidradenitis suppurativa. She didn't want to have children because she didn't want to transmit the disease to them. She didn't trust doctors, she didn't trust the system... She believed nobody was ever going to love her".

***Silvia Lobo**, President, Spanish Hidradenitis Suppurativa Patient Association (ASENDHI)*

This very raw statement offers a glimpse into the reality with which many people suffering from hidradenitis suppurativa (HS) must live.

Hidradenitis suppurativa, also called acne inversa, affects nearly 450,000 people in Spain. However, many of them still do not know this, since they lack a diagnosis that puts a name to what is happening to them.

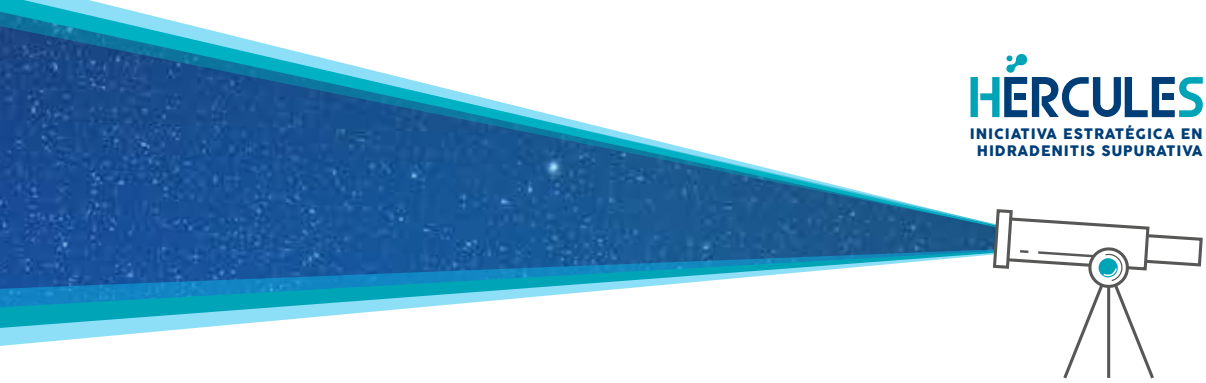
Hidradenitis suppurativa is a chronic disease that goes well beyond mere pimples. It causes pain and a significant decrease in the quality of life of people who suffer from it.

These people must live with not only physical and emotional impairment, but also the stigma and isolation caused by the discharge and odour of these lesions, as well as the fact that this disease is unknown and therefore invisible to society.

This document approaches HS from a holistic point of view — biological, psychological, social and economic — that encompasses all aspects and facets of the disease in an attempt to arrive at a comprehensive, interdisciplinary approach through a simple, efficient healthcare process.

On the one hand, it is intended to raise awareness of this disease on all healthcare and social levels. On the other hand, it is intended to serve as a working tool for healthcare professionals, patients and public administrations to allow a suitable standard of care to be achieved. To do this, feasible recommendations for intervention with an interdisciplinary outlook were proposed. These recommendations will allow the quality of life of people affected by HS to be improved.

The Spanish Hidradenitis Suppurativa Patient Association (ASENDHI) and 20 scientific associations came together to endorse and support this initiative and show their commitment to innovation and continuous improvement, thereby helping to improve knowledge and promote optimal management of this disease.



The scientific associations that endorse this initiative are:

- AD Qualitatem Foundation
- Asociación Española de Gastroenterología, **AEG**
- European Hidradenitis Suppurativa Foundation, **EHSF**
- European Society for Dermatology and Psychiatry, **ESDaP**
- Spanish Academy of Dermatology and Venereology , **AEDV**
- Spanish Association of Gastroenterology , **ANDE**
- Spanish Association of Surgery, **AEC**
- Spanish Federation of Associations of Community Nursing and Primary Care, **FAECAP**
- Spanish General Council Of Official Schools Of Psychologists
- Spanish National Association of Dermatology Nursing and Research on Deterioration of Skin Integrity, **ANEDIDIC**
- Spanish Society of Adolescent Medicine, **SEMA**
- Spanish Society of Emergency Medicine, **SEMES**
- Spanish Society of Family and Community Medicine, **SEMFYC**
- Spanish Society of Gastrointestinal Disease, **SEPD**
- Spanish Society of General and Family Physicians, **SEMG**
- Spanish Society of Health Managers, **SEDISA**
- Spanish Society of Healthcare Quality, **SECA**
- Spanish Society of Hospital Pharmacy, **SEFH**
- Spanish Society of Primary Care Physicians, **SEMERGEN**
- Spanish Working Group On Crohn's Disease And Ulcerative Colitis, **GETECCU**

This document also has the endorsement of:
Asociación de Enfermos de Hidrosadenitis, ASENDHI
European Federation of HS Patient Organisations, EFPO HS

Current situation

Hidradenitis Suppurativa (HS), also known as acne inversa, is a chronic inflammatory skin disease that presents in the form of outbreaks with painful nodules and recurrent abscesses that lead to fistulas. The lesions predominantly occur in the groin, armpits, perineal and/or perianal region and on the breasts and buttocks.

The progressive nature of this chronic disease worsens the situation further, since the pain and recurrent lesions lead to scars that accumulate and reduce mobility, thereby decreasing patient quality of life.

In some patients, serious physical sequelae affect their self-image and self-concept and significantly limit their social relationships, sexual relationships and even ability to work. All this brings stigmatisation and social isolation upon these patients.

Recent studies have demonstrated that patients with HS experience a significant loss of their quality of life comparable to that experienced by patients with COPD, diabetes mellitus, cardiovascular diseases and cancer .

Contrary to what one might think, HS is a **very complex disease with a sporadic and rare familial form**, with an estimated prevalence of more than 1% of the population.

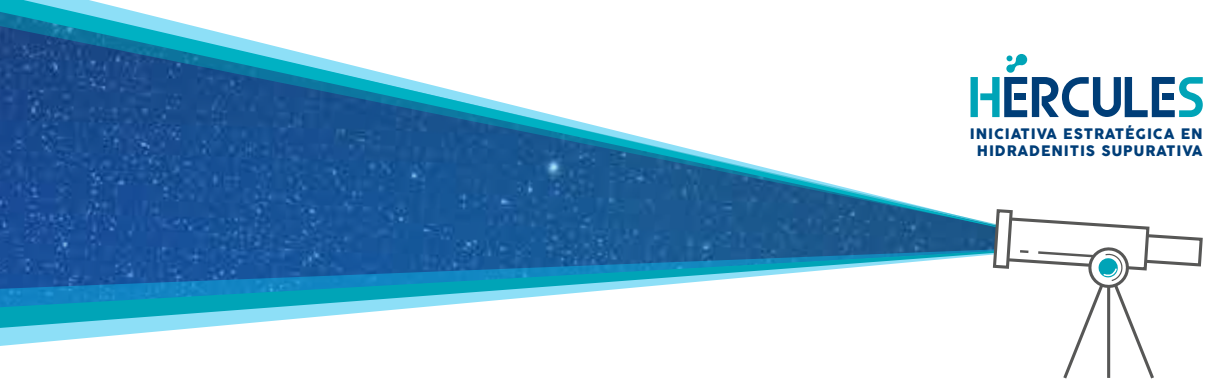
It is an underdiagnosed disease, even though its clinical diagnosis is simple and usually does not require complementary testing. This is because knowledge of this disease is limited and as a result it is sometimes mistaken for other diseases.

The fact that it is a common disease subject to underdiagnosis or delayed diagnosis creates a serious situation in which many patients are trapped in a vicious circle that trivialises their symptoms and forces them to go from clinic to clinic without getting answers about what is happening to them. This causes an absolutely unnecessary feeling of disorientation and suffering.

This situation also creates serious healthcare system inefficiencies and generates an extremely high level of dissatisfaction among HS patients with the healthcare that they receive.

Compared to other high-impact dermatological diseases such as psoriasis (PS), HS generates more visits to emergency departments and involves more hospitalisations[2].

While the cost of management of HS has not been analysed in Spain, studies conducted in Canada and the United States have indicated the high economic impact of the disease both on a direct level (due to hospitalisations and emergency department visits) and on an indirect level (occupational disability)[2,3].



In late 2015, the Spanish Hidradenitis Suppurativa Patient Association (ASENDHI) published the ***Hidradenitis Suppurativa Barometer***[4], a survey administered to a sample of 242 patients with HS that addressed the real problems experienced by patients in Spain.

Some of the conclusions reached by the ***Hidradenitis Suppurativa Barometer***

- The patients stated that it took them nine years on average to get a diagnosis from the onset of their 1st symptom (10 years for women and 8 years for men).
- The patients surveyed visited an average of 14.6 physicians practising different specialities before they got their diagnosis. They mainly visited emergency doctors, followed by cosmetic surgeons, dermatologists, general practitioners (GPs) and general surgeons.
- The departments most commonly visited by patients with HS were emergency departments (58.2% of the times that they went to the doctor due to HS), followed by dermatology departments (16%) and primary care departments (13.8%).
- The patients who were interviewed stated that they had undergone an average of six surgical procedures since the onset of their first symptom (5 years for women and 9 years for men).
- Those interviewed indicated that they had been hospitalised in the last year for two days on average due to their HS and had gone to the doctor on seven occasions.
- Of them, 87.4% stated that HS affected their daily life, and more than 31% stated that it seriously affected their daily life. The main symptoms that they experienced were: pain, discharge, impaired mobility and foul odour.
- The general aspects of their lives that the patients found to be most affected by the disease were:
  - Emotional and psychological problems (20.5%)
  - Sexual relationships (19.9%)
  - Social relationships (16.1%)
  - Occupational problems (15.8%)

9 YEARS
AVERAGE DIAGNOSIS

14,6 PHYSICIANS
AVERAGE PHYSICIANS VISITED BEFORE DIAGNOSIS

6 SURGICAL
AVERAGE

87,4%
STATED THAT HS AFFECTED THEIR DAILY LIFE

35 DAYS
OCCUPATIONAL LEAVE

72,4%
PATIENTS STATED THAT THEY WERE UNSATISFIED OR NOT AT ALL SATISFIED

- Those surveyed indicated that they had lost 27 work days in the last year because they had needed to visit the doctor due to their HS, and that they had been on occupational leave for 35 days on average (30 days for women and 60 days for men).
- Regarding their perception of the healthcare that they received in relation to HS, 72.4% of the patients stated that they were unsatisfied or not at all satisfied.

By way of reflection, comparing these data from the HS Barometer to those presented by the Spanish Federation of Rare Diseases (FEDER) allows the situation faced by patients with HS to be gauged.

- Regarding the diagnosis of rare diseases, the average estimated time that elapsed between the onset of initial symptoms and the arrival at a diagnosis is 5 years. In one out of every five cases, 10 or more years elapsed before a suitable diagnosis was made. The patients with HS placed their average time to diagnosis at 9 years.
- Regarding their satisfaction with the healthcare that they received, FEDER stated that 46.6% of people with a disease considered rare did not feel satisfied. According to the Barometer, 72.4% of people with HS did not feel satisfied.

Es necesario también evidenciar los graves problemas que los pacientes de HS en grado severo tienen para el reconocimiento de la incapacidad tanto temporal como permanente.

The serious problems that patients with severe HS have in achieving recognition of both temporary and permanent disability must also be highlighted.

HS largely affects young people; therefore, it determines and limits their social and occupational integration. Patients, often lacking an accurate diagnosis, face major difficulties in obtaining the reports needed to process permanent disability.

The key to proper management of this type of patient is based on early diagnosis of the problem and comprehensive personalised treatment of the disease.

Thus the many major needs that converge in this disease are highlight[5]:

- Lack of a suitable healthcare process for HS, which would enable an approach that would ensure an optimal standard of care for these patients.
- Lack of awareness of HS, which affects these patients on healthcare, social and institutional levels.

As a result of this situation and the widespread lack of knowledge on HS amongst the public and within healthcare systems themselves, it was decided to promote the launch of a strategic initiative for hidradenitis suppurativa to respond to the specific needs of patients affected by HS.

To do this, a multidisciplinary group of experts from different healthcare fields was formed. These experts, together with patients, wanted to create a comprehensive vision through an interdisciplinary study.

Two basic objectives were established for this initiative: to raise awareness of this disease, and to propose a standard of care for HS together with the interventions needed to achieve it.

The implementation of all proposed measures had to be feasible.

This project attempts to improve the diagnosis, approach and treatment of patients with HS to achieve the best possible care for the patient.

Protocols were approached in a practical, interdisciplinary fashion wherein outlooks on all considerations related to the disease were shared in order to:

- Develop, implement and disseminate a clinical care pathway specific to the disease.
- Promote proper diagnosis of the disease.
- Improve early detection of HS.
- Optimise coordination and ensure healthcare continuity.
- Promote scientific evidence to optimise clinical outcome.

Those who contributed to this document hope that it serves as a springboard for shared reflection by healthcare professionals, decision-makers and society in general in order to offer the response and support to which these patients are entitled.

They would like for this initiative to be joined by all professionals, scientific associations, administrations, patient associations and other entities that may contribute their support to transform the current situation of HS.

The expert group had the support of Eversheds Nicea, which, by contributing its own study methodology, assumed the tasks of coordinating efforts and drafting the final document, as well as energising meetings.

AbbVie helped by providing the logistical support needed to hold in-person meetings and prepare this document.

The expert panel

The 24 experts who helped to prepare this document were:

- **Miguel Ángel Calleja Hernández**
  Pharmacist
  Head of the Hospital Pharmacy Department, Granada Hospital
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  Economist
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  Treasurer, Spanish Association of Health Economics (AES)

- **Javier Carrasco Rodríguez**
  Nurse
  President, Spanish Federation of Associations of Community Nursing and Primary Care (FAECAP)

- **Mercedes Carreras Viñas**
  Nurse
  Galician Society of Healthcare Quality (SGCA)

- **María Jesús Ceñal González-Fierro**
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- **Rosa María Díaz Díaz**
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  Member, Spanish Autoimmune and Systemic Disease Group (GEDEAS), AEDV
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- **Esther Margarit de Miguel**
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- **Sonia Martínez Carmona**
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  Associate Director, El Prat Primary Care Team Management Unit (UGEAP)
  Member, Dermatology Group, Catalan Society of Family and Community Medicine (CAMFiC)

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  Gastrointestinal Medicine Department, Hospital Clínic Universitari de València
  Full-time lecturer in Medicine. University of Valencia
  Coordinating Member, social area, GETECCU

- **David Palacios Martínez**
  General Practitioner
  Spanish national coordinator, dermatology working group, SEMERGEN

- **Elena Polentinos Castro**
  General Practitioner
  Vice Secretary, SEMFYC

- **María Rodríguez Vázquez**
  Pharmacist
  Govermment Affairs Manager, AbbVie

- **Félix Rubial Bernárdez**
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  Manager, Integrated Management Organisational Structure (EOXI), Vigo

- **Teresa Tejero Amoedo**
  Patient Representative
  Manager, ASENDHI

- **Lucía Tomas Aragonés**
  Psychologist
  Aragon Psychodermatology Research Group (GAIP)
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- **Julio Zarco Rodríguez**
  General Practitioner
  General Director, Citizen Care Coordination and Healthcare Humanisation, Autonomous Community of Madrid

Objectives and methodology of the study

Objectives and methodology of the study:

- To generate visibility for hidradenitis suppurativa and its impact on patients' lives.
- To identify the needs for improvement in the healthcare process for the disease and to assess and design the implementation of specific, viable measures that result in the improvement of the tools for the diagnosis, treatment and management of those affected by HS.
- To agree upon feasible recommendations and interventions to be implemented to arrive at a standard of care for patients with HS

A 6-phase study methodology was followed to achieve the proposed objectives.

Specifically, based on a prior questionnaire completed by all panel members, four in-person meetings were held with the entire expert group at which the protocols and recommendations contained in this document could be discussed and agreed upon.

A multidisciplinary approach and an interdisciplinary framework, in which each expert enriched the end result by contributing suggestions from his or her field of knowledge and prior experience, were upheld throughout the process.

In addition, specific working groups were formed to approach subjects that required more pooling of expertise. This was the case of the subjects concerning the diagnosis and management of HS in primary care, paediatrics and nursing.

The purpose of this study was to produce a practical document giving rise to a series of recommendations for simple, feasible implementation in the Spanish National Health System such that gains in quality of life for patients with HS are real, close in time and, at the same time, measurable.

To this end, a system for measuring results through establishing improvement indicators that help to evaluate the impact and return of implementing the recommendations included in this strategic health initiative was planned.

Improvement indicators

An indicator is an observable, measurable characteristic that may be used to show changes or advances in the implementation of a programme or action plan.

To implement a system for measuring objectives, it is necessary to specify: the objectives to be measured, the indicators on which greater or lesser fulfilment of the objectives specified will be assessed, the method to be used for measuring and the different scenarios that may arise.

Since the analysis of the HS situation in Spain was based on a barometer that included quantifying variables that addressed diagnosis, knowledge on HS in the healthcare system and management of HS, indicators related to each of those three objectives were developed and sources that offered data for calculations and interpretation were identified.

The fulfilment of the objectives will be linked to the greater or lesser degree of implementation of the proposals collected in this consensus.

It is recommended that a time frame of 2 to 5 years be established to assess the degree to which the specified objectives have been fulfilled.

Table 1: Proposed improvement indicators

OBJECTIVE 1. To improve the diagnosis of HS in Spain

INDICATOR	SOURCE OF DATA/SOURCE OF VERIFICATION
Reduction of the time from the onset of the initial symptoms to diagnosis	• HS Barometer • ASENDHI survey on social networks • Increase in the number of HS offices and units in public hospitals • Increase in the number of patients from HS-specific units and clinics
Increase in the total number of diagnosed cases of HS	• HS Barometer • ASENDHI survey on social networks • Increase in the number of HS offices and units in public hospitals • Increase in the number of patients from HS-specific units and clinics • Number of referrals by PC or paediatric PC to dermatology • Number of referrals from surgery to dermatology • Number of referrals from emergency medicine to dermatology
Decrease in the mean age at diagnosis	• HS Barometer • Childhood HS Barometer • Increase in the number of HS offices and units in public hospitals • Increase in the number of patients from HS-specific units and clinics • Number of referrals by PC or paediatric PC to dermatology • Number of referrals from surgery to dermatology • Number of referrals from emergency medicine to dermatology
Decrease in the number of physician visits before definitive diagnosis	• HS Barometer • ASENDHI survey on social networks

OBJECTIVE 2. To improve the management of HS

INDICATOR	SOURCE OF DATA/SOURCE OF VERIFICATION
Increase in visits to PC due to HS	• Spanish National Health System information systems
Reduction of the number of emergencies due to HS treated	• Spanish National Health System information systems
Increase in visits to dermatology due to HS	• Spanish National Health System information systems
Increase in training efforts for professionals	• Number of in-person courses to train professionals in inflammatory diseases • Number of in-person courses to train professionals in HS • Number of online courses to train professionals in HS
Decrease in the number of surgical procedures deriving from HS	• Spanish National Health System information systems
Increase in diagnoses of diseases associated with HS	• Spanish National Health System information systems • HS Barometer
Improvement in the rate of satisfaction with the healthcare system of HS patients	• HS Barometer • EsCrónicos Barometer
Reduction in the percentage of smokers among HS patients	• Spanish National Health System information systems • HS Barometer
Reduction in the percentage of overweight patients	• Spanish National Health System information systems • HS Barometer
Increase in the number of papers and posters at events for SAs	• Number of papers at conferences, seminars and other events for scientific associations
Increase in the number of research efforts on HS	• Number of research efforts, trials and projects on HS
Increase in the number of scientific and informative publications	• Number of publications

OBJECTIVE 3. To increase knowledge of HS

INDICATOR	SOURCE OF DATA/SOURCE OF VERIFICATION
Increase in the number of searches for HS on the internet and social networks	• Analytical tools on the internet • Analytical tools on social networks
Increase in the number of ASENDHI members	• Number of ASENDHI members
Increase in the number of patient training activities	• Number of in-person courses to train patients in inflammatory diseases • Number of in-person courses to train patients in HS • Number of online courses to train patients in HS
Implementation of awareness-raising efforts and campaigns	• Number of efforts and campaigns on HS • Impact of efforts and campaigns on HS (amount of materials distributed, number of appearances on communication media, number of people attending the efforts, etc.)
Increase in the number of appearances on communication media	• Number of appearances on communication media talking about HS
Preparation of the 2nd study on knowledge of hidradenitis suppurativa in the general population	• Second study on knowledge of hidradenitis suppurativa in the general population

Hidradenitis suppurativa in the first person

*By **Silvia Lobo***
Patient with HS in Hurley stage III and ASENDHI president

My name is Silvia and I am a hidradenitis suppurativa patient.

When I first arrived in proctology, I could not even breathe without pain. I underwent surgery on a perianal fistula. When I received the discharge report, I saw the name of my disease for the first time: hidradenitis suppurativa. I was 28 years old.

I was 13 when I had my first "pimples". At first, they came and went. My outbreaks tended to coincide with my menstrual periods. From age 27 on, there were no longer any outbreaks, but the pain did not stop. The medication had no effect on me, the pain made me weep and I couldn't sleep. I lost my job.

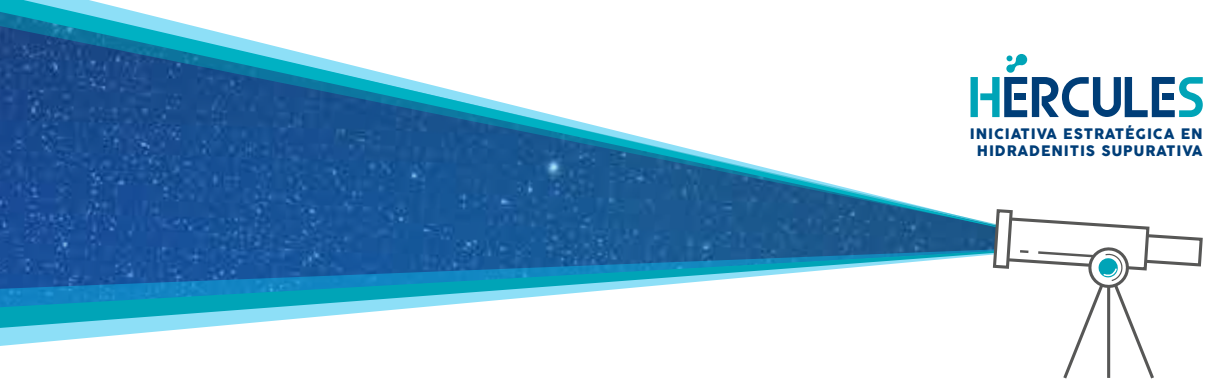
Since I was 28, I have had 6 major operations: three pilonidal sinus operations, two perianal fistula operations and one abdominal dermolipectomy.

Five of the six operations had to be performed in the last two and a half years. I have yet to undergo operations on both sides of the groin, the labia majora and the area between the buttocks.

> *« I suppose that living with any chronic, incurable disease is complicated. Living with a chronic, incurable disease, which is also painful and causes festering lesions that give off an unpleasant odour, sometimes becomes unbearable. »*

The day-to-day life of a person with HS is dictated by the disease.

Omeprazole and painkillers are our breakfast. Next, a shower frees us of the unpleasant odour of discharge and relieves us of the discomfort and pain. Then there is the wound-dressing session, which may take between ten minutes and an hour.



For us, picking out clothing to wear is no small matter. We can't wear just anything. Our underwear must be made of cotton, and be as simple and as smooth as possible. Any lace or band might mean going out without any wounds and coming back with them.

We don't get to follow fashion. We don't wear jeans, we don't wear tight pants, and we definitely don't wear light clothing. Dark clothing lets us hide unexpected discharge from a wound that we sometimes can't stop, no matter how much gauze we layer on. That's why our bags amount to bona fide medicine cabinets: gauze, ointments, painkillers, tissues, pads, etc.

A lesion may form, develop and discharge pus on a single day, anywhere.

Like everybody else, we've got to work, and at the same time it's hell for us. Spending 8 hours sitting or standing can become torture. Some days, we can't even walk.

When your groin, perineum, lower belly, thighs or buttocks are inflamed and discharging pus, leaving home turns into an ordeal.

When you finish your workday, you're so sore that all you want is to lie in bed and sleep. The pain is physically and mentally exhausting.

Outbreaks are unpredictable, and when they happen, they stop you from going about your daily life. This means that we often have to go on leave. Nobody understands this, and many of us are stigmatised for it.

Nowadays, three short periods of leave in less than two months amount to legal grounds for dismissal, and so we often find ourselves in a bind: either we take longer periods of leave, or we go to work however we can.

HS patients do not see themselves as handicapped or disabled.

On top of all this, people don't know what's happening to you. They think that whatever is going on isn't so bad, and as a result, many patients end up more and more alone.

Family and friends eventually disappear. In the most serious cases, HS affects all aspects of our lives: sexual relationships are not as they should be, and there are no vacations, parties, plays, movies and so on, because there are times when we can barely move, walk or remain seated for very long.

Solitude is one of our common denominators.

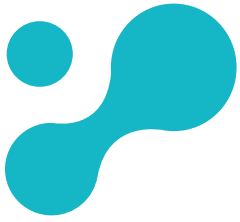
The surgical procedures are complicated, and so are the post-operative periods, especially for those who must face these situations alone.

Many HS patients smoke and/or are overweight. These two circumstances negatively influence our disease since they act as aggravating factors or promote poor wound healing. However, the anxiety caused by our solitude, pain and inability to lead the lives that we would like to lead is hard to manage.

This is where anxiolytics, endocrinologists and nutritionists come into play.

Living with HS is a constant struggle. The Spanish Hidradenitis Suppurativa Patient Association (ASENDHI) attempts to support patients and their families and assist professionals and managers. At the same time, we ask that

> *« we all help each other to make HS a known, recognised disease, since when that is the case we will be able to have more and better tools at our disposal to address the problems that we face in our day-to-day lives. »*



Description of the disease

Hidradenitis suppurativa (HS), also called acne inversa, was described by Velpeau in 1839, although it is traditionally attributed to Verneuil.

It is a chronic inflammatory disease with an onset as early as puberty. It is more common in women, and is clinically characterised by inflammatory nodules (Figgure 1) in intertriginous areas (Figure 2 and 3), which may spontaneously drain a malodourous substance and converge in the deep dermis to form extensive areas of inflammation which heal with scars that are sometimes deforming (Figure 4).

This set of signs and symptoms causes a significant decrease in patient quality of life, even greater than that experienced by patients with extensive psoriasis.

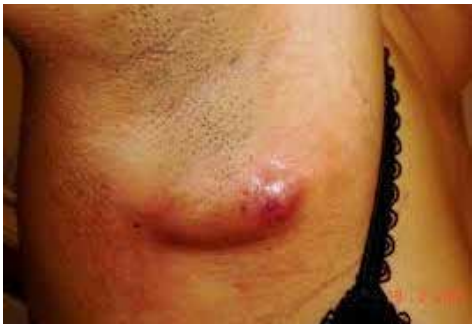


Figure 1: Inflammatory nodule.

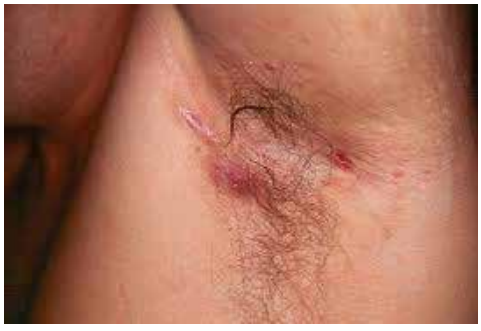


Figure 2: Scars and fistula.

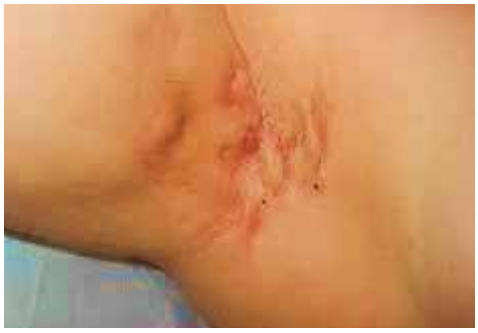


Figure 3: Open comedones.

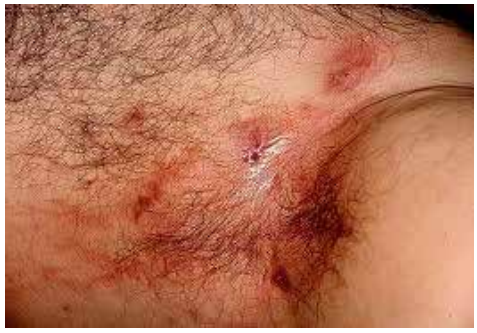


Figure 4: Polymorphic lesions.

The presence of double comedones in folds as HS precursor lesions and cases of paediatric onset4, have also been described.

There are several types of HS classification and staging. Some are qualitative, such as Hurley staging10. Others are quantitative, such as the Sartorius11 and modified Sartorius, Hidradenitis Suppurativa Physician Global Assessment (HS-PGA), and Hidradenitis Suppurativa Clinical Response (HiSCR) classifications.

In clinical practice, the most commonly used staging system is the Hurley staging system. This author divided patients into three groups: stage I, stage II and stage III, depending on the presence and extent of scars and sinuses (Table 2). This classification is very commonly used due to its simplicity and speed of use.

Table 2: Hurley HS classification stages

Hurley stage I	Hurley stage II	Hurley stage III
One ormore	Separated in space and recurring over time	Multiple

Hurley stage I lesions

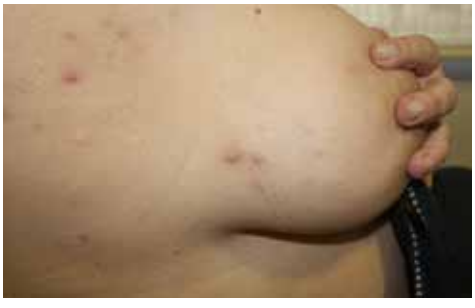


Figure 5: HS lesion, Hurley stage I, breast area.

Figure 6: HS lesion, Hurley stage I, axillary area.

Hurley stage II lesions

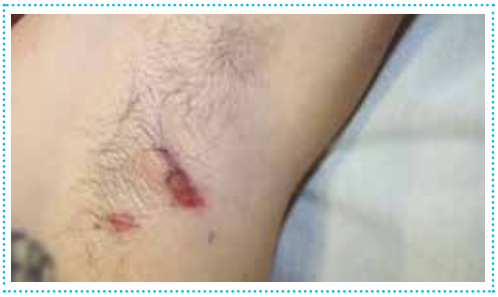


Figure 7: HS lesion, Hurley stage II, axillary area .

Hurley stage III lesions

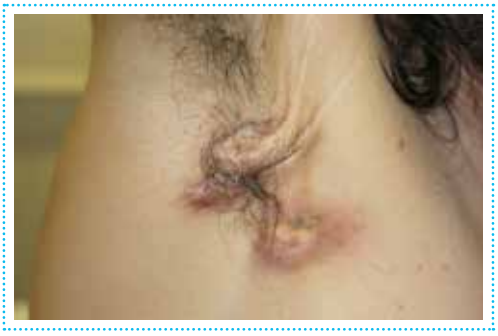


Figure 8: HS lesion, Hurley stage III, axillary area.

Figure 9: HS lesion, Hurley stage III, inguinal area.

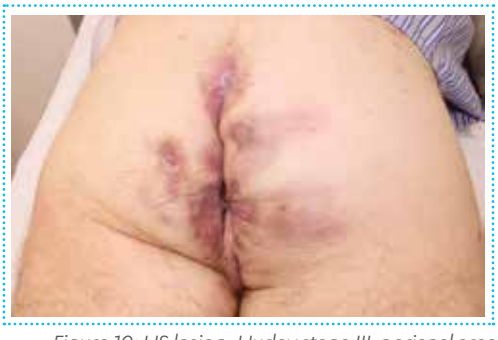


Figure 10: HS lesion, Hurley stage III, perianal area.

Moreover, the Hurley scale is based on some characteristics of the disease that are fixed/invariable, such as scars and fistulas. Therefore, it is not useful for assessing therapeutic response.

In clinical trials, the Sartorius classification tends to be used. It is more complete since it includes the anatomical regions involved, the number and type of lesions, the distance and presence of normal skin between lesions, a visual analogue scale for pain, and a questionnaire to measure patient quality of life (DLQI).

The Sartorius classification was subsequently modified by Sartorius (modified Sartorius score) and then by Revuz (Sartorius score modified by Revuz).

The original Sartorius scoring assesses each area affected by HS in isolation and assigns a score to (i) each type of lesion, (ii) the distance between two significant lesions and (iii) the lesions being separated by healthy skin. The sum of all these factors yields an overall score.

The modified Sartorius score modifies the previous scoring by simplifying it and focusing it more on the presence of inflammatory lesions, with the intention of improving its usefulness for assessing therapeutic response.

The authors recommend complementing it with a determination of pain using a visual analogue scale (VAS) and with the number of boils presented in the last month reported by the patient.

Interobserver variability in the modified Sartorius score has been demonstrated to be low, and it is positively correlated with the presence of risk factors and with other measurements of seriousness (such as the DLQI). However, its applicability is limited in serious cases.

One of the current classification models most commonly used in clinical trials to assess therapeutic response is the Hidradenitis Suppurativa Physician Global Assessment (HS-PGA). This divides the seriousness of the disease into different categories, taking into account all abscesses, fistulas, inflammatory nodules and non-inflammatory nodules present (adding together all areas affected).

The latest HS-PGA developed divides seriousness into 6 different degrees:

- **Clear**: no inflammatory nodules or inflammation.
- **Minimal**: presence of non-inflammatory nodules only.
- **Mild**: fewer than 5 inflammatory nodules or an abscess or draining fistula with no inflammatory nodules.
- **Moderate**: fewer than 5 inflammatory nodules or an abscess or draining fistula and one or more inflammatory nodules or 2-5 abscesses or draining fistulas with fewer than 10 inflammatory nodules.
- **Serious**: 2-5 abscesses or draining fistulas with 10 or more inflammatory nodules.
- **Very serious**: more than 5 abscesses or draining fistulas.

- Recently, a new score for HS severity classification was suggested by EHSF after an extensive Delphi procedure. This score, the international HS4 (IHS4), is an easy to use, validated tool to assess severity of hidradenitis suppurativa. After regression analysis it became apparent that the nature of lesions was an important parameter to be considered. Thus, a discriminant analyses and Delphi voting the following scoring system was accepted: 1 point for each nodule,2 points for each abscess and 4 points for each fistula with mild disease up to 3, moderate from 4 to 10, and severe more than 10. This scoring system classification exhibited strong correlation with Hurley (r=0.638), expert opinion (0.741), Modified Sartorius (0.699) and PGA (0.767).

1 X EACH NODULE + 2 X EACH ABSCESS + 4 X EACH FISTULA

- 3 or less: mild
- 4-10: moderate
- > 11: severe

T. Tzellos; European Hidradenitis Suppurativa Foundation. Validation of HS4 scoring system and development and validation of a novel scoring system to assess hidradenitis suppurativa severity. Experimental Dermatology 2017 (O17-2).

HS is diagnosed clinically. Imaging tests are useful as they demonstrate the extent of the lesions in depth.

HS has a heterogeneous histopathological pattern. The most significant characteristics are infundibular hyperkeratosis *(follicular plugging)* and perifolliculitis. Perifollicular infiltrate is mixed with certain CD8+ epidermotropism. Both of these things precede follicle rupture.

Hyperplasia of the follicular epithelium, which will lead to a sinus that will grow horizontally, and interfollicular psoriasiform hyperplasia are also very common12.

The course of the disease involves recurrent outbreaks with variable severity and a tendency to remit as early as the sixth decade of life[13].

In 2013, Canoui et al.[14] divided 600 patients with HS into three phenotypes according to lesion location: mammary axillary, follicular and gluteal. The authors established differences with respect to frequency, predominant sex and clinical course in each group.

More recently[15], a subgroup called *fulminans* was described. This subgroup consists of male patients of Afro-Caribbean origin with serious disease, both in terms of extent and sequelae, and in terms of a high number of recurrences, in which skin lesions are preceded by arthritis and keratitis.

EARLY LESIONS	LATE LESIONS
The differential diagnosis should be with: • Acné • Carbuncles • Cellulitis • Cutaneous blastomicosis • Demoid cyst • Erysipelas • Furuncles • Inflamed epidemroid cysts • Lymphadermopathy • Perirectal abscess • Pilonidal cyst • Staphylococcal infection • Simple abscesses	They must be differentiated from: • Actinomycosis • Anal fistula • Cat scratch disease • Crohn disease • Granuloma inguinale • Ischiorectal abscess • Lymphogranuloma venereum • Nocardia infection • Noduloulcerative syphilis • Ilonidal disease • Tuberculous abscess • Tularemia • Neoplasms, primary or secondary

The **differential diagnosis** with other diseases is proposed based on the course of the disease and the location of the lesions[6,16].

Since 2000, many patients with HS and other associated diseases have been described[17]. Although cases associated with keratitis[17] and Down syndrome have been published[19], the highest number of publications have referred to patients with HS and inflammatory bowel disease, with or without severe inflammatory acne and/or arthritis[20-26].

The response of these different entities to the same treatment strengthens the hypothesis that all symptoms are manifestations of a single autoinflammatory phenomenon[23-26].

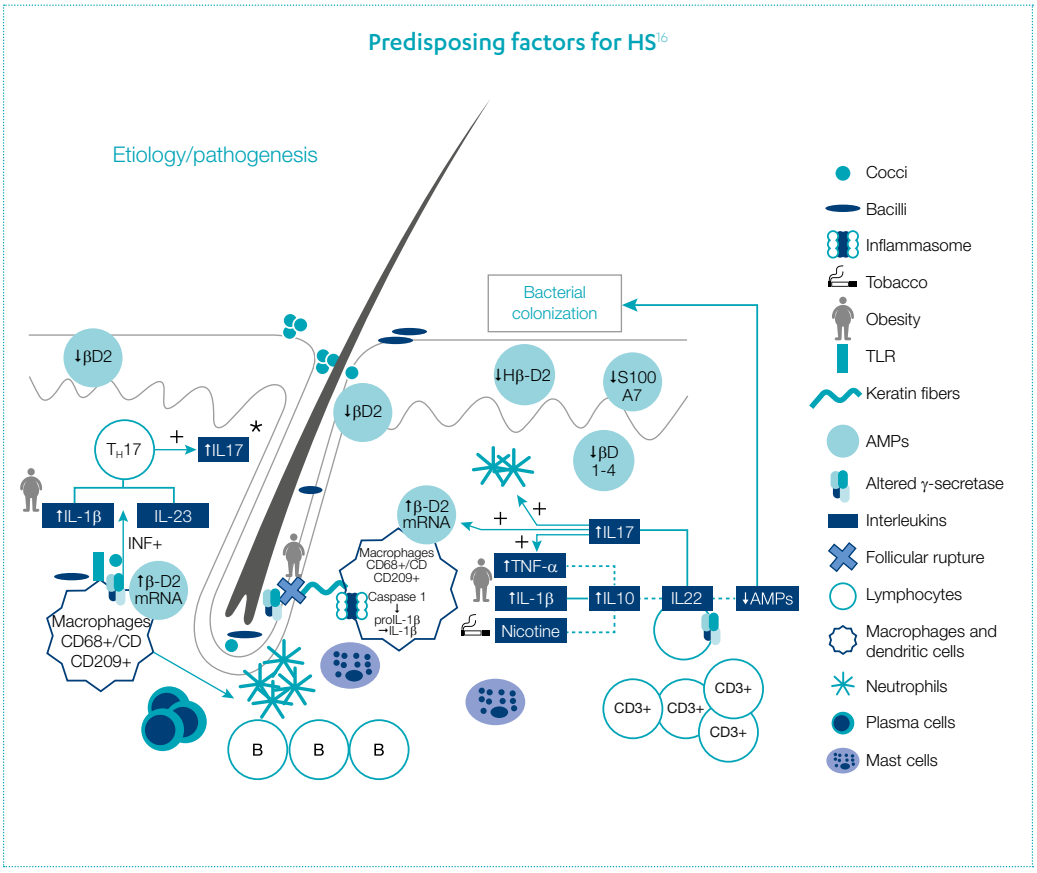
Aetiopathogenesis and triggering and/or predisposing factors for HS

The aetiopathogenesis of the disease is unknown[27-32]. As indicated, HS is a multifactorial follicular inflammatory disease.

The genetic factor has been demonstrated in less than 50% of cases. Its presence is associated with a worse prognosis.

Despite advances in research on the causes of the disease, to date, no biological or clinical marker exclusive to HS can be said to exist.

Figure 11.



(Martorell et al.)

In recent years, the so-called "unifying theory" of the pathogenic mechanism, which includes genetic abnormalities (gamma-secretase and the Notch signalling pathway), environmental factors and different microbial flora abnormalities, has gained importance (Figure 11). There is an imbalance between the different cytokines with very high levels of IL-1β and TNF-α.

Inflammation of the inflammasome that leads to high-molecular-weight keratins has also been described.

Neither the function of the bacterial microbiome demonstrated by means of biopsy nor that of the biofilm that covers the fistulas is well understood. They could be linked to the onset of the disease or to its perpetuation.

It is likely that, in the future, specific antibiotic therapy will be administered and also efforts will be made to modify the bacterial microbiome, rather than eradicate it, by means of flora transplantation and the use of synthetic antimicrobial peptides.

Otros factores predisponentes o desencadenantes[33-43]:

- **Smoking**: approximately 70% to 88.9% of patients who suffer from HS are smokers. The nicotine in tobacco stimulates IL-1033 overproduction and is linked to Y-secretase and Notch50 signalling pathway dysfunction.
- **Obesity**: this is considered an aggravating factor more than a triggering factor. Metabolic syndrome, like other autoimmune disorders, appears to have a statistically significant link to HS. In addition, mechanical irritation, occlusion and maceration play a role in exacerbation.
- **Endocrine factors**: the predominance of cases in females, the existence of premenstrual outbreaks, the onset of the disease after menarche or in adolescence and the improvement experienced by some patients during pregnancy or following menopause supported the hypothesis of hyperandrogenism. However, treatment with oral hormonal contraceptives or reductase inhibitors has not achieved the therapeutic response rates expected, and hormonal laboratory studies in affected patients have not supported these hypotheses.
- **Tight clothing**: shear forces and friction stimulate the onset of lesions due to follicle rupture.
- **Deodorants or hair removal**: irritants act as aggravating factors for the disease.
- **Drugs**: lithium, contraceptives and isotretinoin are among the medicines that may generate repeated outbreaks of the disease.

Prevalence, incidence and comorbidities

Epidemiological aspects

La mayor parte de los estudios publicados que analizan aspectos epidemiológicos de la HS Most of the studies published analysing epidemiological aspects of HS have been conducted in a European or North American population. Given that no studies have been conducted in a Spanish population, at least in the literature reviewed to conduct this study, the estimated data in the populations mentioned will be referred to below.

There is a great deal of variability in the scientific literature in relation to the **prevalence** data reported. This may likely be attributed to differences in terms of populations and methodologies between the different studies designed to estimate this parameter.

Multiple publications have cited values of 1% to 4% making reference to the data obtained in a study by Jemec et al.[3] conducted in a Danish population in the 1990s.

A subsequent study, published in 2008 by Revuz et el.[35], conducted by means of surveys sent to a French population over 15 years of age, estimated a prevalence of HS of 0.97%.

The only population study conducted to calculate the prevalence of HS was done in the United States, specifically Minnesota, where a value of 0.13% was estimated. This value was substantially lower than those previously reported. This difference was attributed to methodological considerations, as this was a population study, and to the overestimates that other studies had probably made in which the diagnosis was assumed based on surveys completed by patients with no objective confirmation.

Other North American studies have confirmed prevalences lower than 1 per 1000, such as one by Cosmatos et al.[44], a retrospective study conducted based on a database of verified patients that estimated a value of 0.053%, and one by Shlyankevich et al., a retrospective case–control study that determined a prevalence of 0.08%[45].

Some factors that would explain the lack of data and the limited information on the population with HS, apart from the absence of a patient registry and the relative research attention paid to HS to date, could be as follows

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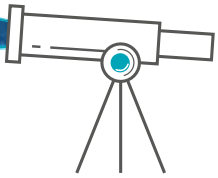


- Patients are not always treated by healthcare teams in the same speciality, since, based on different circumstances, they visit primary care, emergency medicine, surgery or dermatology indiscriminately, sequentially or according to no particular protocol.
- Those with mild forms do not end up at hospitals, the main places where registries are constructed.
- The disease goes by various names: carbuncle, abscess, boil, hidradenitis. Sometimes different names are used to diagnose the same entity, making it difficult to compile data properly.

One problem that arises in determining the prevalence of HS is the fact that there are different International Classification of Diseases (ICD) codes for recording HS, even though they refer to the same disease with different signs.

In this sense, it should be noted that the term **"Hidrosadenitis Suppurativa", which many Spanish patients and professionals call the disease, does not have an assigned ICD code, therefore the use of the international name, "Hidradenitis Suppurativa", is recommended".**

Table 3. ICD-10 codes by which HS may be coded

ICD code	Diagnosis
705.83	Hidradenitis
706.2	Sebaceous cyst
364.60	Idiopathic cyst
685	Pilonidal cyst
685.1	Pilonidal cyst without abscess
685.0	Pilonidal cyst with abscess
709	Other skin and subcutaneous tissue diseases
682.5	Cellulitis and abscess of buttock
682.8	Cellulitis and abscess of other specified sites
682.9	Cellulitis and abscess of unspecified sites
682.3	Cellulitis and abscess of upper arm and forearm (except hand)
682.2	Cellulitis and abscess of trunk
682	Other cellulitis and abscess
616.4	Other abscess of vulva

With respect to **age distribution**, although cases of paediatric onset have been described, the disease usually starts following puberty, generally in one's early 20s, and tends to remain active during one's 20s and 30s. It has also been observed that women often experience improvement following the onset of menopause, and therefore patients with continued disease activity from age 50 on tend to be male.

In relation to **distribution by sex**, HS has been seen to be more common in women than in men.

Based on the data from the studies published, the female:male ratio has been quantified as approximately 3:1. The values reported in some of the most significant studies vary widely and include 2.6:1 (Canoui-Poitrine F. et al.14 and Schrader AM et al.[46]), 2.8:1 (Cosmatos I. et al.[44]), 3.1:1 and 3.3:1 (Revuz JE et al.[47]).

Moreover, a retrospective Dutch study (Schrader AM et al.[46]) observed that women had an onset of the disease at younger ages, a higher frequency of breast and inguinal lesions and a higher frequency of a family history of HS, whereas men had a higher frequency of serious disease, gluteal and perianal lesions, and a personal history of serious acne.

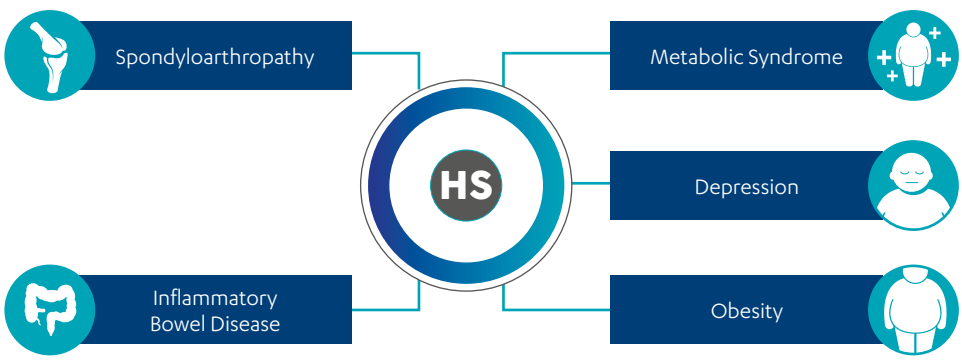
The subject of ethnic or **racial distribution** has hardly been addressed in the scientific literature. Very few studies providing objective data in this regard have been conducted. A recent retrospective study in a North American population showed that HS is more common in African Americans (Reeder VJ. et al.[48]).

Comorbidities and diseases associated with HS

In the course of HS, diseases associated with this condition, known as comorbidities, have been described. Among them, HLA B27 negative arthritis and inflammatory bowel disease (IBD), especially Crohn's disease (CD), are the two chronic inflammatory diseases most often associated with HS, with an incidence of HS associated with arthritis of 0.7%-1% (Martorell A. et al.[49]) and an incidence of HS associated with IBD of 16% (van der Zee, HH. et al.[26]).

Together with all this, the chronic inflammation that HS entails on a systemic level is associated with a higher frequency of metabolic syndrome (MS). Sabat et al.[50] observed a higher prevalence of MS ($p < 0.05$, odds ratio [OR] 4.46), as well as the majority of its criteria, including central obesity (OR 5.88), high triglycerides (OR 2.24), low HDL cholesterol (OR 4.56) and hyperglycaemia (OR 4.09), compared to a healthy control population. Notably, the presence of MS disproportionately affects a higher number of young patients with HS (patients < 35 years of age) (OR 6.18).

In addition, a higher presence of depression and other psychological problems in HS patients than in healthy people has been confirmed[51].



Economic burden of the disease

Preliminary considerations for the economic analysis of the costs associated with HS

An analysis of the economic burden represented by a disease must be based on an analysis of the disease and of the determinants that the disease entails both for the health system and for the patients that suffer from it.

As indicated in previous sections, HS is a chronic immune disease of the follicular epithelium that causes recurring discharging lesions, abscesses, nodules, draining fistulas and scars, in addition to severe pain in the skin areas at the same time.

An analysis of the burden that any disease represents for the system must be based on an analysis of the type of disease, its clinical course, which population it mainly affects, how it affects the daily lives of patients, how it is treated, etc.

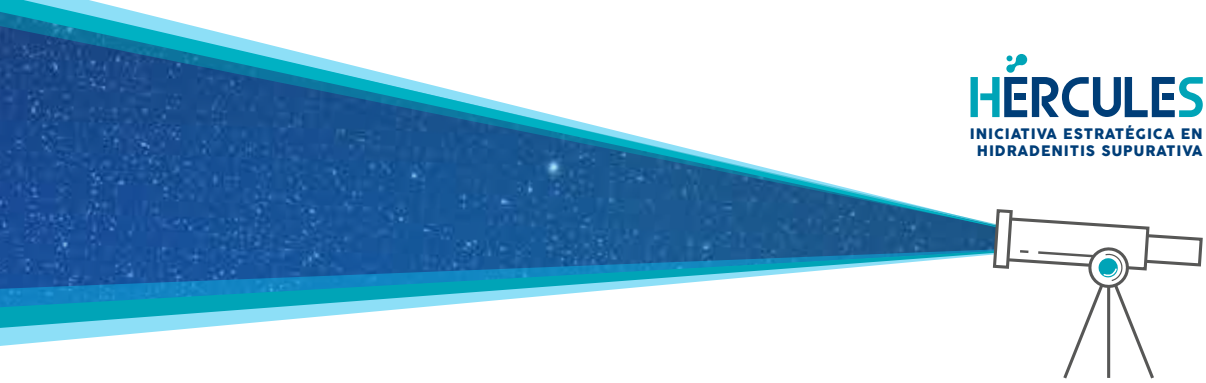
Although HS may appear at any age, it usually appears in young adults. In general, the most active stage of the disease is up to 50-55 years of age. In addition, women are more likely than men to suffer from HS[52].

In keeping with an estimated prevalence around 1%, there are believed to be approximately 450,000 people with this disease in Spain.

Regarding the levels or stages of seriousness of the disease, the scale usually most commonly used, the Hurley scale[10], comprises three — Hurley stage I, II and III — based on the type, number and extent of lesions.

Similarly, based on the seriousness of the disease, there may be said to be four types of treatment for HS[52-54]:

- **Treatment by obstructing the hair follicle-retinoids**: this tends to be administered over long periods of 6 to 12 months.
- **Treatment by managing the inflammatory response:** (I) corticosteroids, which require short regimens; (II) immunosuppressants; (III) biologics (adalimumab). If there is a satisfactory response to the treatment, they require continuous regimens for years[52,54].



- **Treatment for superinfection:** antibiotics (tetracyclines or a combination of rifampicin and clindamycin), which require regimens for 3 months.
- **Other:** Antiandrogens and surgical treatments.

In addition, as indicated above, HS has a major impact on patient quality of life compared to other dermatological diseases. Patients tend to be absent from work and take several weeks of occupational leave per year, since the severe, constant pain in each outbreak prevents them from going to work, and the surgical procedures that they must undergo also oblige them to take prolonged occupational leave.

In addition to this prolonged leave, more work days are lost due to various medical appointments that they must attend as well as wound-dressing sessions, which especially affect the costs that patients must bear due to having HS.

Disability data are unknown, as it is difficult to quantify the expenditure corresponding to patients whose disease prevents them from going about their work, and who would therefore be candidates for temporary or permanent disability. This is because the disease does not tend to be considered a cause of temporary or permanent disability.

Here it is important to stress the need for HS to be recognised as a cause of disability or handicap. This is demanded by patients who, as seen in a previous chapter, cannot balance severe stages or outbreaks of the disease with an active life from an occupational point of view.

In addition, HS is associated with a variety of concomitant and secondary diseases such as obesity, metabolic syndrome, inflammatory bowel disease, spondyloarthropathy and depression. These would also be reflected in the analysis of burdens represented by the disease for the system and for patients.

Cost analysis

Any cost analysis should depend on the different stages of the disease, from the perspective of a baseline setting (financier or public healthcare system). The essential argument is that the direct cost of the disease advances as the disease progresses, and the cost related to HS could basically be approximated by understanding that it would include everything related to loss of occupational productivity.

Table 4: Proposed direct and indirect costs

PROPOSED COSTS	
Direct healthcare service costs: management of the disease and all its potential complications	Healthcare visits: primary care, specialist, nursing, other professionals, emergency services
	Use of medicines
	Hospitalisations, primary care, etc.
	Testing and material: diagnostic and laboratory
	Medical transport
	Other
INDIRECT COSTS	
	Loss of occupational productivity

In addition, to estimate the costs associated with a certain disease, in this case HS, matters such as the perspective of the study, on which the economic costs included in the analysis will depend, as well as the availability of updated and real data, should be considered.

The best known **perspective** for calculating the economic burden of a disease is that of the **supplier or financier** (service provider) since it comprises only direct costs, both healthcare costs and non-healthcare costs.

There is also the **patient perspective**, which takes into account the costs and effects experienced by patients who suffer from this type of disease.

In addition, the **study approach**, which may be prevalence or incidence, should be taken into account. The former refers to the study of costs incurred by the disease in patients in a certain region over a given period of time. The latter estimates the costs incurred by a disease up to its outcome, and is most useful in estimating the effect of a treatment on future costs.

Moreover, data on the use of healthcare resources to care for HS patients may be regarded from two different perspectives: one that considers costs from the initial time to the future (prospective) and one that considers data for past, known events, as would be the case mentioned in this study (retrospective).

Therefore, the costs to be analysed would be as follows:

- **Direct costs**: those directly related to the use of resources as a result of detection, treatment, investigation and follow-up of the disease. They are divided into (I) healthcare costs (measures of hospitalisation, medicines for treatment, visits with specialists, transport needed to receive treatment, etc.) and (II) non-healthcare costs (professional care, non-professional care, etc.).
- **Indirect costs**: those related to losses of productivity (occupational leave, etc.) as a result of the limitations generated in the patient's life by the clinical course of the disease itself.

Breaking down the set of variables above yields a diagram like the one shown in Table 5.

Table 5: Variables to be included in the cost analysis

POPULATION OF INTEREST
Inclusion criteria
Patients ≥ pre-established age Patients diagnosed with HS Exclusion criteria: it would be necessary to determine the reason
Data source and selection
Electronic medical records, pharmacy supply records, primary care medical record
Description of the variables to be analysed
Demographic variables: Date of birth Sex Level of education Occupational situation
Clinical variables: Diagnosis and classification Disease duration (date of diagnosis) Annualised rate of outbreaks, date of last outbreak and next-to-last outbreak Quality of life measured with a pre-established scale Mortality

Treatment
Prescribed treatment (type of administration, dose, healthcare resources needed for its administration) Prior treatments used for HS purposes Use of resources (the form in which the cost will be presented — mean annual cost per patient, etc. — would also have to be indicated)
Direct healthcare costs
Outpatient visits: Número de primeras visitas: especialista, otros profesionales... Número de visitas sucesivas: especialista, otros profesionales...
Primary care: Number of visits: family physician, nursing, primary care, emergency medicine, other professionals, etc.
Hospitalisation: Hospital of admission Number of hospitalisations in the period Unit of hospitalisation Days of hospitalisation Reason for admission
Emergency department: Emergency department (hospital) Number of visits to emergency medicine in the period Reason for emergency care (HS or other reasons) Days of admission to emergency medicine Treatments used in emergency medicine and hospitalisation at a day hospital Number of stays Treatments received (medication required, etc.)
Diagnostic tests related to HS: Diagnostic tests related to the associated comorbidity
Indirect healthcare costs
Loss of occupational productivity (number of days of occupational leave). This may be approximated well using specific questionnaires and the mean total occupational cost from the quarterly occupational cost survey. These costs would then basically be applied to patients of working age (not retired)
Type of descriptive analysis of variables Description of techniques to minimise confounding factors and screening bias (techniques for regression, stratification, etc.)
Statistical package that will be used with an established level of statistical significance The methodology used should take into account various scenarios to be assessed based on the sample size considered in each case. The levels of significance to be used should be the standard ones (*** $p < 0.01$, ** $p < 0.05$ and *** $p < 0.10$).

Preliminary data

Taking into account the considerations above, preliminarily, based on the different sources consulted in addition to different extrapolations, in 2014, the **average annual cost per patient in Spain who had been diagnosed with HS at least one year prior would be above €3,000.** Naturally, this Figure could vary by areas affected, lesion types, Hurley stage (I, II or III), number of comorbidities and degree of use and assignment of unit cost of healthcare services (primary care, specialist and emergency medicine).

Specifically, **the estimated total annual cost of HS based on the above-mentioned assumptions would exceed €1 billion.** This Figure is very different if it is distributed by autonomous community, probably due to both regional differences between regional health services and the variable prevalence of the disease.

It should also be pointed out that most total costs refer to direct costs.

Patients with HS require an average personal expenditure (indirect costs) that would be above €500 per year. The majority of this cost would correspond to the acquisition of medicines, special clothing and transport to receive treatments in addition to the payment of private medical insurance and losses in occupational productivity.

€3000
AVERAGE ANNUAL COST PER PATIENT

€1 billion
TOTAL ANNUAL COST OF HS

€500 per year
AVERAGE PERSONAL EXPENDITURE

Finally, it should be pointed out that, in addition to the above-mentioned approximation of the economic burden of the disease from a cost perspective,

it would be important for studies to proliferate in Spain on the social return on investment of the approach, in this case, to HS, and for these studies to be conducted from a multidisciplinary perspective.

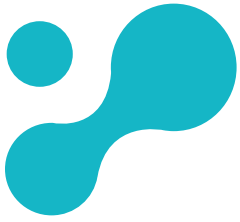
With this, its impact in clinical, healthcare, economic and social terms could be quantified and optimal strategic planning of the healthcare resources available could be undertaken.

Thus, specific results could be obtained on how each euro invested in treatments to improve the quality of life of patients with HS achieves a much greater social return (gains in health and lower future healthcare expenditure) than if there is no optimal approach to this disease.

Recently, from the perspective of health economics, so-called *Social Return on Investment* (SROI) has been used as a methodological tool to analyse and quantify the repercussions and social value of the activity of an intervention or organisation for society.

These studies determine whether the management and treatment given to a disease offer a suitable response to all patient needs, especially in diseases with a significant social and personal impact like HS, and quantifies patient needs to plan actions that meet them.

In summary, a proper, timely diagnosis of HS is an essential element in the social return of a new approach to this disease, as it would save unnecessary medical visits and lead to better treatment and management of HS. It would also increase the well-being and empowerment of patients diagnosed with HS as well as prevent unnecessary occupational leave and the resulting losses of productivity affecting the young and occupationally active population in many cases.



Diagnosis of HS

As indicated in the introduction, according to the data collected by the Barometer, the patients consulted stated that it took them nine years on average — eight for men and ten for women — to get a diagnosis of HS.

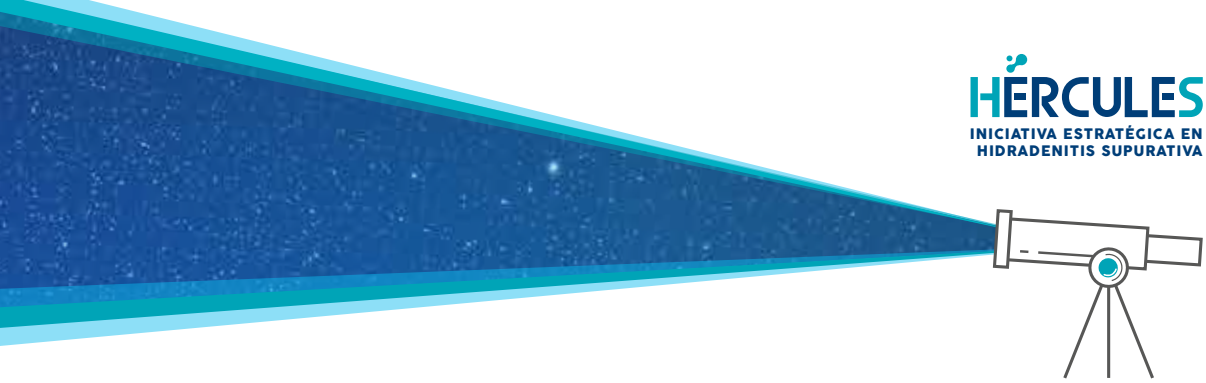
In addition, close to 20% of patients stated that they learned that they suffered from HS not through a physician, but through other means such as information accessible on the internet, friends and family members. In addition, the patients indicated that they had visited an average of 14.6 physicians from the onset of their first symptom to their definitive diagnosis, and that the emergency department was the department that they visited most during that time.

Given the initial data collected by the Barometer, the considerations submitted for debate with the expert panel were particularly intended to attempt to identify the reasons underpinning such a late diagnosis; to specify the measures to be taken to accelerate the definitive diagnosis of HS; and to determine a simple, clear and easy-to-use diagnostic algorithm to facilitate identification of the disease.

The debates held among the experts comprising the multidisciplinary panel for this strategic health initiative identified various potential reasons as to why a disease with a prevalence that cannot be considered rare or uncommon is diagnosed so late.

These potential reasons may be grouped into two types. The first would be that HS is sometimes mistaken for other diseases. The second would be related to the characteristics of the healthcare system, as well as the characteristics particular to the disease (painful outbreaks requiring care in the moment), which cause the patient not to always visit the same physician, which means that the recurrence of lesions, one of the main criteria for the diagnosis of HS, cannot always be detected.

With respect to diagnostic confusion, the establishment of a number of clear, simple *red flags* allowing the specialist, essentially the GP, to consider HS when faced with a certain type of lesion was identified as indispensable. To do this, the **dissemination of clear graphic material for lesions** allowing clear identification of those that characterise HS based on disease stage was stressed as necessary.



The specification of the diagnostic algorithm that appears later on in this chapter establishes clear criteria for the diagnosis of HS.

It is important to point out that HS is **diagnosed clinically** and therefore may be diagnosed by performing a suitable patient examination and asking questions intended to discover the recurrence of outbreaks as appears in the algorithm.

Subsequent chapters will explore the approach to HS in PC in greater depth and specify what the medical history and patient examination, as well as the management of HS once it has been diagnosed, should comprise.

Regarding the difficulty of tracing the patient's disease, the establishment of a suitable health-care process that starts with an accurate

early diagnosis, as well as some protocols for management and referral that allow the patient to be followed up by both the GP and the dermatologist in the most serious cases of the disease, will allow HS patients to move through the system without losing healthcare continuity or care and follow-up of their disease.

Diagnostic algorithm for HS

As indicated, the diagnosis of HS is a clinical diagnosis, as it does not require the use of additional technology such as ultrasound, which could indeed be useful in subsequent assessment of the extent of the lesions (as will be seen later on in this document) and staging of the disease, as well as if there is clear diagnostic uncertainty.

MAJOR CRITERIA FOR DIAGNOSIS OF HS

- **THE TYPE OF SKIN LESIONS THAT THE PATIENT HAS:**

  HS clinical skin lesions are polymorphic, but tend to manifest with deep, painful, inflammatory lesions including nodules, fistulas and abscesses[49].

- **LOCATION:**

  It most often affects the armpits; groin; buttocks; and perianal, perineal, breast and submammary areas. In women, it is more common for the submammary, axillary and inguinal areas to be affected, whereas in men it is more common for the gluteal and perianal areas, as well as more atypical locations such as the nape of the neck and the area behind the ears, to be affected.

- **RECURRENCE:**

  Two or more outbreaks in the last six months constitute recurrence, which is considered clearly suspected HS.

MINOR CRITERIA THAT MAY AID IN THE DIAGNOSIS OF HS

- **FAMILY HISTORY OF HS**

  According to the data collected by the HS Barometer, 26.5% of patients interviewed had an average of 1.8 family members also diagnosed with HS.

- **LACK OF FEVER**

  Patients with HS did not have fever, unlike patients with other inflammatory diseases.

- **LACK OF LYMPHADENOPATHY**

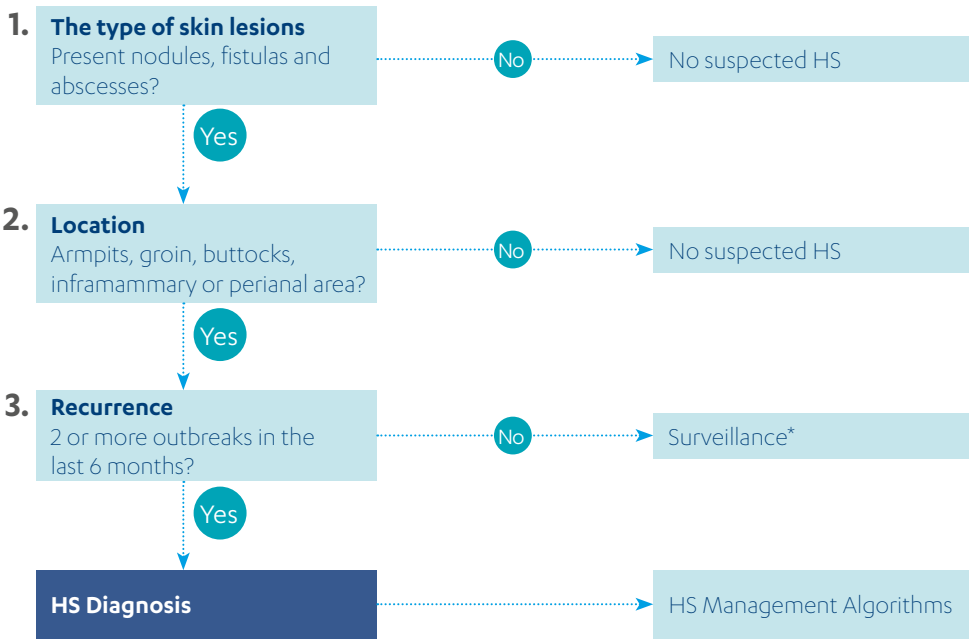
  As a differential factor, patients with HS also lacked lymphadenopathy.

Based on these diagnostic criteria, the following diagnostic algorithm has been designed. Its main objective is to achieve simplicity such that HS starts to be diagnosed at the gateway to the healthcare system, i.e. mainly primary care but also emergency departments.

To do this, **widespread dissemination of the algorithm is recommended**, accompanied by images of typical lesions for each stage of HS, as this is essential for promoting detection of the disease.

Figure 12

Diagnostic algorithm for HS



* Other indicators that help the diagnosis of hidradenitis suppurativa:

- Family history of HS
- Absence of fever
- Absence of lymphadenopathy

Source: Prepared by the authors based on discussion by experts.

Differential diagnosis

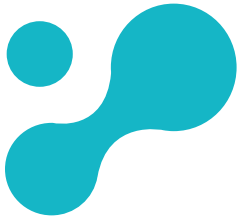
In case of diagnostic uncertainty, the differential diagnosis should be established with: local pyodermitis such as folliculitis, boils, simple abscesses, erysipelas and cellulitis; skin manifestations of Crohn's disease, especially in forms with a predominance of perianal fistulas; primary or secondary neoplasms, lymphogranuloma venereum, actinomycosis and scrofuloderma[57].

Recommendations to be implemented to improve the diagnosis of hidradenitis suppurativa

1. **Disseminate the diagnostic algorithm for HS** through the scientific associations for family medicine and primary care, community and primary care nursing, and emergency medicine of the Spanish regional health services using electronic platforms to support healthcare or printing on paper of clear leaflets that present **both the algorithm and the images of the lesions most characteristic** of HS.

2. Promote and develop **training efforts among primary care and emergency department professionals** for knowledge of HS and criteria for its diagnosis through scientific associations and regional health services, **using both in-person and *online* training through new technologies and social networks**.

3. Establish some **warning mechanism (*red flags*)** in the information system to help prevent diagnostic confusion of HS with other diseases.



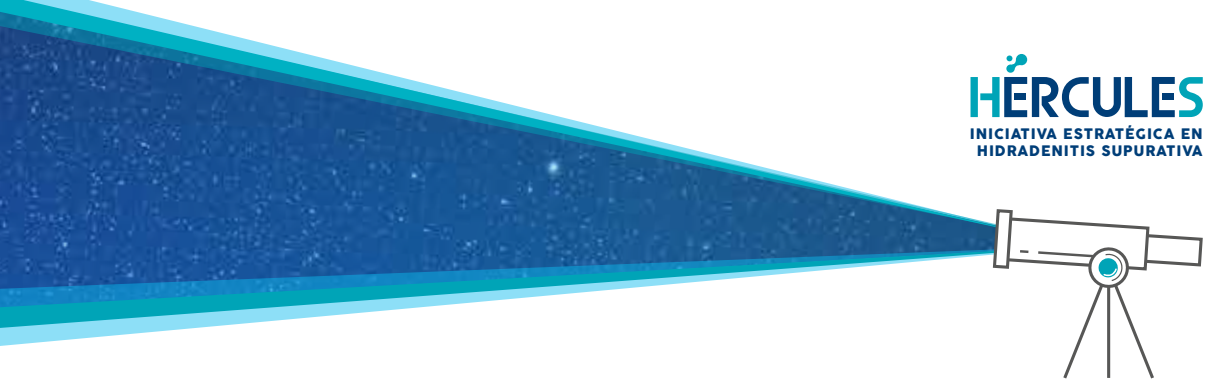
Management of HS in primary care

Primary care (PC) plays a fundamental role in the identification, diagnosis, treatment and care of people with HS; in the prompt adoption of general measures in view of the onset of the first symptoms; and in the assessment of the degree of severity whereupon the patient is referred, as applicable, to the dermatologist, who will decide upon the therapeutic need of the patient.

For the HS patient, the PC team should become a reference — a gateway to the healthcare system to which he or she may turn with questions, outbreaks and complications — so that this healthcare level may suitably manage patient needs; refer the patient to dermatology or other specialists if required; and provide the patient with the training, information and healthcare resources needed for the care of his or her disease.

If the data provided by the HS Barometer concerning the role that PC currently plays in the management of the disease are kept in mind, it is confirmed that little more than 9% of patients surveyed stated that they had been diagnosed by their family doctor of them, 23.6% stated that their referring doctor was their GP (following 52.4% who stated that their referring doctor was their dermatologist). Concerning the role of nursing, although the results were not limited to PC alone, it is worth noting that more than 51% believed that nursing should "play a significant role in the care of HS and be a point of communication between the specialist physician and the patient", even though more than 54% stated that in the care of their disease "nursing only intervenes at specific times (some wound-dressing session, etc.)".

As a general conclusion of the discussions with the expert panel, and a starting point with respect to the standard of care for primary care teams in the management of HS, it may be affirmed that PC should lead the monitoring and management of the patient with HS in mild stages of the disease (Hurley stage I), but not to the detriment of visits to dermatology or any other specialists that may be required based on the course of the disease. Therefore, suitable tools should be offered to PC healthcare teams such that they are genuinely capable of detecting, treating and managing these patients.



Objectives of primary care in HS

Primary care objectives in relation to HS should be as follows:

Diagnostic objectives of HS

- to aid in early detection
- to perform clinical management by assessing the degree of severity
- to establish personalised treatment and follow-up of patients by promoting preventive measures
- and to address both diseases associated with HS and complications deriving from HS.

1. Early detection

The previous chapter addressed the diagnosis of HS by determining the criteria for diagnosis as well as the decision-making algorithm to conclusively diagnose, or not diagnose, suspected HS as such.

It should be pointed out that many patients with HS receive an erroneous diagnosis (carbuncles or abscesses) and that the majority of them receive antibiotic regimens that are not suitable for their actual disease.

As indicated in the chapter on diagnosis, if there are recurring episodes in the areas typically affected, HS should be suspected.

Therefore, any patient with the characteristic lesions in the typical areas following a chronic course in the form of outbreaks who visits primary care should be actively questioned and the following physical examination should be performed:

CLINICAL ASSESSMENT OF A PATIENT WITH SUSPECTED HS IN PRIMARY CARE

Medical history

- Toxic habits (smoking)
- Medical history
- Active treatment (lithium, contraceptives, isotretinoin)
- Family history of HS
- Presence of pruritus, pain, fever
- Aggravating factors: tight clothing, use of deodorants
- Associated diseases (acne conglobata, pilonidal sinus, dissecting cellulitis of the scalp)
- Gastrointestinal symptoms: abnormal intestinal rhythm, rectal bleeding (Crohn's disease)
- Course: duration, history of previous and recurring outbreaks

Physical examination

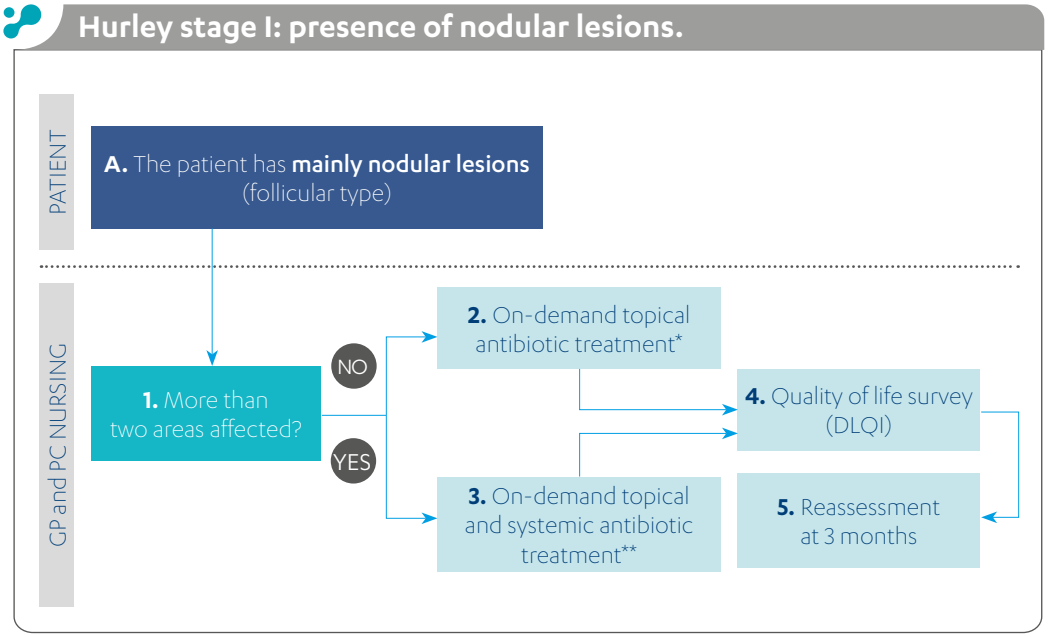
- General:
  - Vital signs: Temperature (temp.), blood pressure (BP)
  - Body mass index (BMI)
  - Cardiorespiratory and abdominal examination
- Skin **(observe and palpate lesions)**
  - Type of lesion:
    - Primary lesions: painful solitary nodules that may progress to abscesses and drain spontaneously or following excision, fistulas
    - Secondary lesions: hypertrophic scars, indurated plaques
    - Tertiary lesions: open comedones with one or more follicular openings
  - Location
  - Extension
  - Existence of pain on palpation
  - Existence of heat, reddening
  - Presence of oedema
  - Associated regional lymphadenopathy
- General examination of all anatomical regions with apocrine glands: armpits, external genitalia, submammary and intermammary areas, groin, perianal area, and buttocks

2. Clinical management and follow-up

For proper clinical management of HS in primary care, following clinical assessment, the degree of severity (Hurley stage I, II or III) will be assessed, and the actions taken will be based on this assessment.

The protocols for management recommended for each stage of the disease based on the type of lesion that the patient has appear below.

Figure 13. Management of the patient with HS in PC.

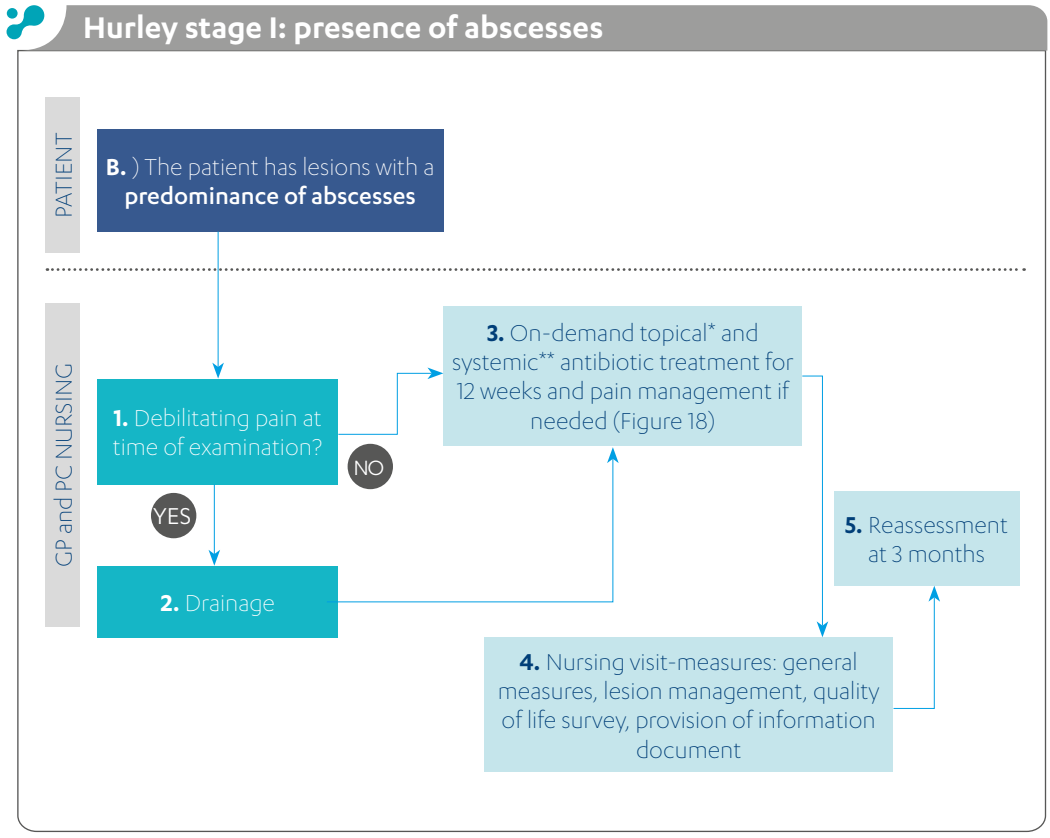


*/** *Zouboulis CC et al 2015,52*

Start: The patient has mainly follicular nodular lesions.

1. Does the patient have lesions in more than two areas?
2. If the patient has lesions in one or two areas, on-demand topical antibiotic treatment will be prescribed (clindamycin 1% topical or resorcinol 15% in excipient O/W)*.
3. If the patient has lesions in more than two areas, both topical and systemic antibiotic therapy will be prescribed (tetracycline 500 mg/12 hours or doxycycline 100 mg/day or minocycline 100 mg/day)**. A 12-week treatment regimen will be established.
4. Regardless of the number of areas affected by the lesions, the patient will complete the quality of life survey, specifically the DLQI or the reference survey.
5. Whatever the treatment prescribed based on the number of areas in which lesions occur, the patient will be given an appointment in three months for follow-up and reassessment.

Figure 14. Management of the patient with HS in PC.

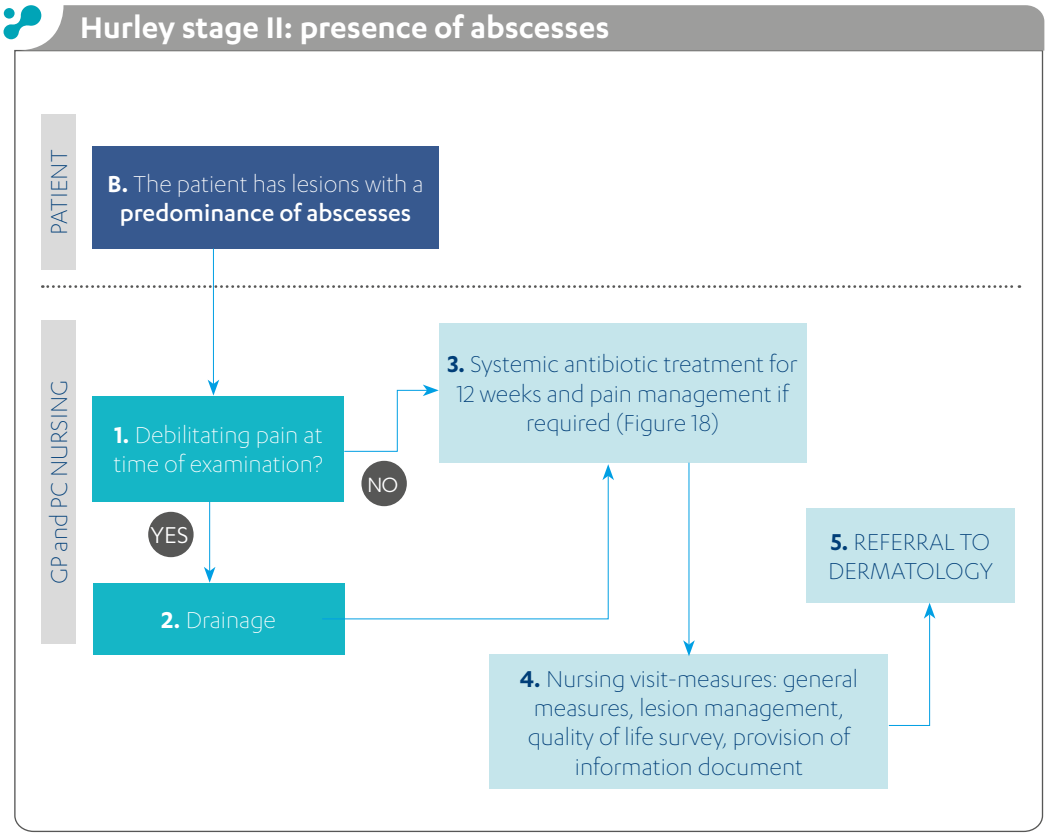


/ Zouboulis CC et al 2015,52*

Start: The patient has lesions with a predominance of abscesses.

1. Do the abscesses cause debilitating pain on examination?
2. If abscess(es) cause debilitating pain, their drainage by the physician or nursing professional is indicated.
3. If they do not cause debilitating pain and do not require drainage at that time, as well as following drainage if required, on-demand and topical and systemic antibiotic treatment will be prescribed, specifically tetracycline 500 mg/12 hours, doxycycline 100 mg/day or minocycline 100 mg/day**. A 12-week treatment regimen will be established. Pain management if the patient requires it (Annex 1).
4. The patient will be given an appointment for a nursing visit to be informed on general measures (healthy living habits, smoking, general information on HS, regimens for self-care of lesions, etc.), management and dressing of lesions, and a quality of life survey (DLQI or the reference survey used).
5. The patient will be given an appointment in three months for follow-up and reassessment by the GP.

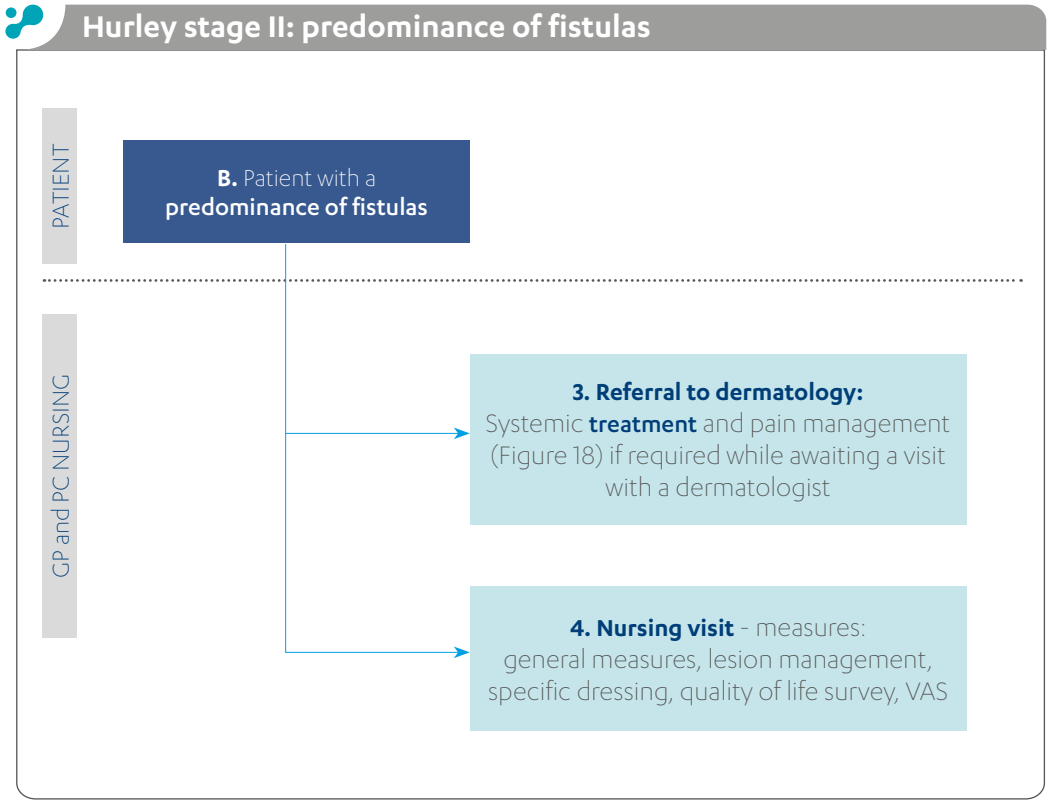
Figure 15. Management of the patient with HS in PC.



Start: The patient has lesions with a predominance of abscesses that have not responded or have partially responded to treatment.

1. Have two prior cycles of antibiotics already been prescribed in the last six months?
2. If the patient has undergone a single antibiotic cycle in the last six months, repeat systemic treatment for 12 weeks and pain management if required.
3. If the patient has already been prescribed two cycles of antibiotics in the last six months, he or she will be referred directly to dermatology and pain management measures will be applied if required.
4. In both cases, the patient will be given an appointment for a nursing visit to be informed on general measures (healthy living habits, smoking, general information on HS, regimens for self-care of lesions, etc.), management and dressing of lesions, a quality of life survey (DLQI or the reference survey used), etc.

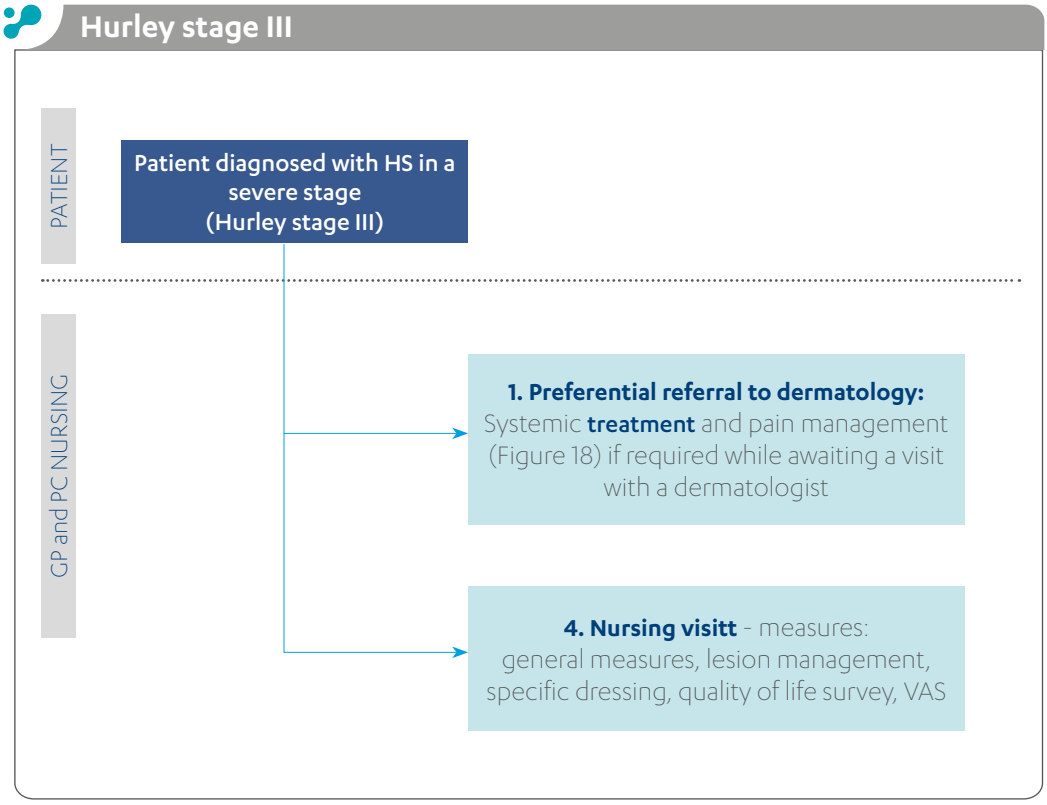
Figure 16. Management of the patient with HS in PC.



Start: The patient has lesions with a predominance of fistulas.

1. The patient will be referred to dermatology. The patient will be prescribed a regimen of topical and systemic antibiotic treatment (tetracycline 500 mg/12 hours or doxycycline 100 mg/day or minocycline 100 mg/day**) and measures for pain management (Annex I) will be applied during the waiting time for the visit with the dermatologist.
2. The patient will be given an appointment for a nursing visit to be informed on general measures (healthy living habits, smoking, general information on HS, regimens for self-care of lesions, etc.), management and specific dressing of lesions, a quality of life survey (DLQI or the reference survey used), etc.

Figure 17. Management of the patient with HS in PC.

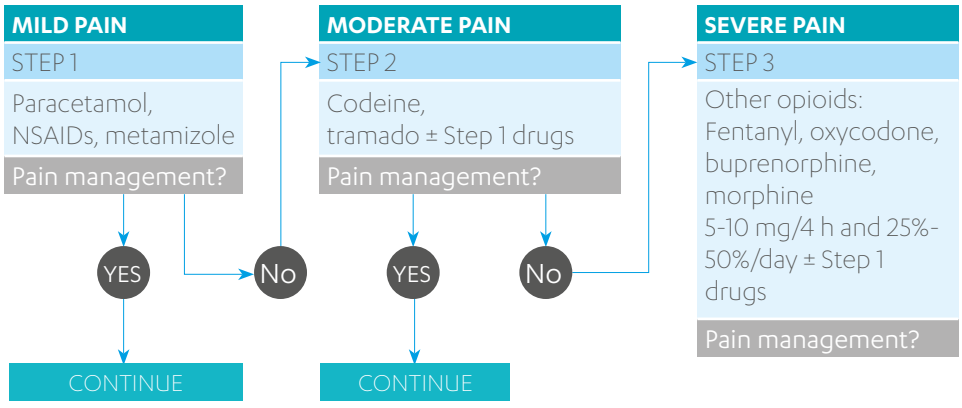


Start: Patient diagnosed with hidradenitis suppurativa in a severe stage (Hurley stage III).

1. Referral to dermatology. The patient will be prescribed a regimen of topical and systemic antibiotic treatment (tetracycline 500 mg/12 hours or doxycycline 100 mg/day or minocycline 100 mg/day**) and measures for pain management (Annex I) will be applied during the waiting time for the visit with the dermatologist.
2. The patient will be given an appointment for a nursing visit to be informed on general measures (healthy living habits, smoking, general information on HS, regimens for self-care of lesions, etc.), management and dressing of lesions, a quality of life survey (DLQI or the reference survey used), etc.

Figure 18.

WHO analgesic ladder



The nursing visit

As may be seen in the healthcare processes presented, the nursing visit is considered an essential part of the process. The goal is for

- Patient to have access to as much information as possible on his or her disease
- To know how to adopt habits that prevent the onset of outbreaks or exacerbations
- To suitably monitor patient quality of life and detect other conditions early while
- Providing suitable care according to the standard determined for each type of lesion

Bellow it is specified what should be the content of the nursing consultations in the field of the health center.

NURSING VISITS IN THE HEALTHCARE CENTRE

a. Clinical assessment of the patient

Nursing will work with the physician to collect data which should be included in the patient medical record through the medical history and the physical examination so that all significant data, both static (medical history, toxic habits, lesion location, lifestyle, profession, etc.) and dynamic (weight, height, BMI, BP, heart rate, etc.), are compiled in the record.

In addition, the results of the following tests will be applied and recorded:

- Visual analogue scale (VAS) on pain and pruritus.
- DLQI, a scale to measure the impact of the disease on patient quality of life.

The HADS, which measures emotional impact or impairment, may be administered to the patient depending on his or her emotional condition and whether he or she grants consent.

b. Therapeutic patient education

Regarding patient training/education, at the nursing visit, the patient will be provided with information on his or her own disease. It is very useful to be able to provide the patient with an explanatory leaflet on HS. This leaflet should be available at all primary care centres.

This leaflet, whose publication is recommended, must contain:

- General information on HS: Definition, explanation of the different stages of the disease, etc.
- Hygiene rules for a better prognosis for HS (soaps, use of hair removal, type of clothing advised, etc.) and healthy living habits that help to reduce outbreaks (weight management, smoking cessation, etc.).
- Contact details and sources of information to which the patient may turn such as the patient association and other accredited sources.

Annex II to this document includes the proposed contents for these leaflets.

General care such as smoking cessation and weight management should be stressed at the visit.

c. Perform wound-dressing and teach the patient self-care

The nursing professional will perform wound-dressing for the skin lesions and will tell the patient how to perform self-care of these lesions. The manner in which wound-dressing is performed depends on the type of lesion. Annex I to this document details what is understood to be an appropriate standard for each type of care based on the lesion to be treated.

d. Administer treatment and show the patient how to do it

The nursing professional will inform the patient on how to apply his or her treatment and will offer precise instructions on its application and storage if needed.

3. Preventive measures

Preventive measures must be actively recommended to all patients with HS from the time of diagnosis.

The role of nursing is key in education and recommendation of healthy lifestyles: smoking cessation, prevention of overweight, appropriate clothing, etc.

As explained in the previous point, preventive measures will represent one of the main elements of nursing visits.

4. Approach to complications and associated diseases

The role of primary care is fundamental in the approach to the associated diseases that the patient may have such as metabolic syndrome, follicular occlusion diseases and Crohn's disease.

Primary care must take a personalised, comprehensive and interdisciplinary approach by assessing complications that may derive from the disease itself (contractures, anal fistulas, etc.) as well as complications secondary to the major impact on patient quality of life (depression/anxiety). Proper coordination between PC and the different healthcare levels is key.

Recommendations for improving the management of HS patients in PC

1. **Disseminate healthcare processes for the management of HS and promote their implementation in the Spanish National Health System with the involvement of Scientific Associations** for family medicine dermatology, community nursing and PC, as well as the involvement of Spanish regional health services.

2. **Publish and disseminate an information leaflet for patients** accessible at primary care centres and provided to the HS patient by his or her primary care team.

3. **Publish and disseminate the standard of care** presented in Annex I to this document at primary care centres and dermatology departments.

4. **Promote and develop training efforts for PC teams** to improve their knowledge of HS and the criteria for diagnosis and care.

5. **Pilot mechanisms for quick referral to dermatology** in cases of diagnostic uncertainty as well as painful and recurring outbreaks.

HS in childhood and adolescence

While the approach to HS is complex in adults, it is even more complex in children and adolescents. When one is in the midst of biological, psychological, sexual and social development, it is very difficult to accept a painful, foul-smelling disease that leaves scars and has no cure.

HS is uncommon in children and adolescents. The signs and symptoms of paediatric HS are similar to those of adult HS, with the onset of painful, exudative nodules and abscesses and fistula tracts that recur in the armpits; groin; and genital, gluteal and perimammary regions. Thus it is a debilitating disease with a high impact on patient psychosocial well-being and quality of life.

As few studies have been conducted on the disease in those under 18 years of age, little is known about the unique epidemiological, clinical and therapeutic features of this disease when it appears at young ages.

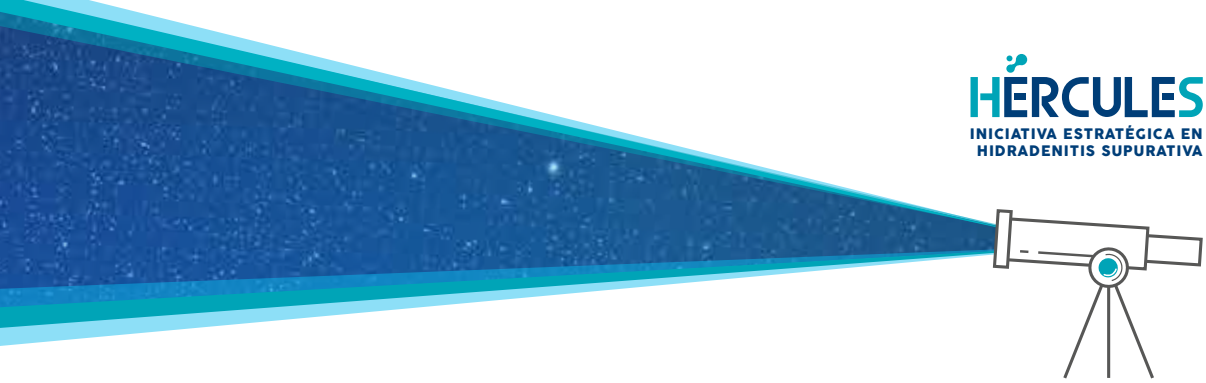
HS tends to appear following puberty, usually between one's teens and 20s. Although the disease tends to be diagnosed in early adulthood, it is not uncommon for symptoms to start years earlier, in adolescence, during puberty or immediately after puberty[58]. However, it is rare in prepubescent children, and some studies refer to these cases as **early-onset hidradenitis suppurativa**[59]. It is estimated that HS of prepubescent onset, before 11 years of age, occurs in 2% of patients 60 with HS. The earliest onset of HS referred to in the literature occurred in a 5-year-old girl[61].

44%
PATIENTS
with HS started before **18** years

The prevalence of HS is unknown. However, the HS Barometer published in Spain in 2015[4] estimated that: 3% of patients started to experience symptoms before 11 years of age, 22% of patients started to experience symptoms between 11 and 14 years of age, and 19% started to experience symptoms between 15 and 16 years of age. Thus, according to these data, 44% of patients with HS started to experience symptoms before 18 years of age.

Recently, a multicentre study[62] was published to assess the percentage of HS in each Hurley stage in the adult population and in the adolescent population.

Out of a total of 528 adult patients and 62 adolescents, it was confirmed that 10.6% of adult patients have Hurley stage I disease, 60% have Hurley stage II disease and 29.4% have Hurley stage III disease, whereas, 17.7% of adolescent patients have Hurley stage I disease, 74.2% have Hurley stage II disease and 9.1% have Hurley stage III disease.



A familial form of hereditary HS, with an autosomal dominant inheritance pattern in the majority of cases, has been described[63]. A number of problems in hair follicle differentiation could be the key to the aetiopathogenesis of HS64. Although these mutations have not been described in any paediatric cases, patients with early-onset disease appear to tend to have affected family members more often than patients with later-onset diseases[65].

In childhood, as in adulthood, HS is more common in obese patients66 and has appeared to be associated with metabolic syndrome67. Moreover, this disease is known to be strongly linked to smoking68. In the childhood form, the majority of patients with early-onset HS in published cases had not started to smoke before the onset of the disease (although their exposure to secondhand smoke was not recorded).

Another unique feature of childhood HS that should be stressed is the higher likelihood of it appearing together with hormonal abnormalities. Cases of paediatric patients with HS with adrenal hyperplasia, obesity and metabolic syndrome have been published. A diagnosis of HS in children may be a marker of early puberty.[69]

Moreover, due to a lack of specific studies in children and adolescents, it is not possible to determine the extent to which they suffer from anxiety, depression and other psychiatric abnormalities, which are more prevalent in HS in adults.

Although, in general, childhood HS tends to be more mild and have fewer symptoms, it is accepted that its clinical manifestations overlap with those of adult HS and that nodular lesions may be complicated and ulcerate, fistulise or lead to painful abscesses. As childhood HS progresses, as in adult HS, inflammatory lesions converge and leave hypertrophic or retractile scars.

The same scales used to classify the disease in adults may be used to classify the disease in children and adolescents: Hurley staging, classic or modified Sartorius scoring, the overall assessment performed by the physician or the hidradenitis severity index.

Ultrasound may be considered more important in children and adolescents, since it enables early diagnosis even in forms with few symptoms and allows diagnosis of pseudocysts, fluid collections and fistula tracts, which will reflect disease activity more objectively and which may be very important for classifying these patients as accurately as possible and achieving suitable follow-up[70].

In summary, it may be said that childhood HS, like adult HS, is an underdiagnosed disease, and that therefore

- the main recommendation is to identify it properly when the patient arrives at the healthcare system and refer the patient to the dermatologist for proper staging.

The paediatric management of the disease should be similar to the management proposed for adults, with an emphasis on:

- **Early diagnosis** with a proper medical history and full examination
- **Clinical assessment** of HS severity with ultrasound support
- **Use of intervention protocol** (diagnostic and therapeutic algorithm)
- **Assessment** of potential complications and associated diseases: Sometimes a multidisciplinary approach will be required
- **Nursing support**
- **Prevention**: Healthy living habits: diet, smoking, clothing, etc.
- **Psychological support**: It is important to adjust patient and parent expectations to reality. This is a chronic disease that will accompany the patient throughout life, with few reprieves along the way. At an age when many physiological and psychosocial changes are happening or soon to happen, facing a chronic, hard-to-manage disease with inevitable episodes of pain and malodourous discharge can be very frustrating. Children and adolescents tend not to ask for help, and it is our duty to offer it to them, through specialised support to help them to accept and face chronic, stigmatising diseases like HS.

Recommendations to be implemented to improve the management of HS in children and adolescents

1. **Promote and develop training efforts for paediatricians** to improve their knowledge of HS and the criteria for diagnosis and care.

2. Disseminate the diagnostic algorithm through paediatric scientific associations.

3. Promote relationships between paediatrics, dermatology and all other specialities to facilitate quick, suitable referral of the child suffering from HS such that the sequelae left by the disease are minimal.

4. Promote the HS case registry In childhood and adolescents.

5. Promote paediatric HS studies that provide information on its incidence and prevalence, associated comorbidities, etc.

6. Publish and disseminate Information leaflets for parents and families of paediatric patients.

Management of HS in dermatology departments

To date, efforts have been made to clarify how HS may be diagnosed early as well as how the disease should be managed in primary care once it has been diagnosed based on its stage.

HS, as described initially, is a chronic inflammatory skin disease of dermatological manifestation. Therefore, **its reference specialist is a dermatologist**.

With a view to achieving equitable management of the disease in all specialised departments, regardless of which healthcare centre the patient visits, the standard of care for a patient diagnosed with HS in a dermatology department appears in this chapter.

As a preliminary consideration, it should be noted that, in the debates held within the expert panel that participated in this strategic health initiative, both professionals and patients revealed the dearth of scientific and clinical information available on the disease and the approach to the disease. This, together with the underdiagnosis of the disease, the dispersion in the healthcare system of the patients affected (PC, surgery, dermatology, emergency medicine, etc.), the limited visibility of the disease, etc., means that, in some cases, dermatologists themselves require more training and information on HS. For this reason, **it is recommended that the Spanish Academy of Dermatology and Venereology (AEDV) implement some initiative that increases knowledge of the disease**, its implications and its impact on the lives of patients.

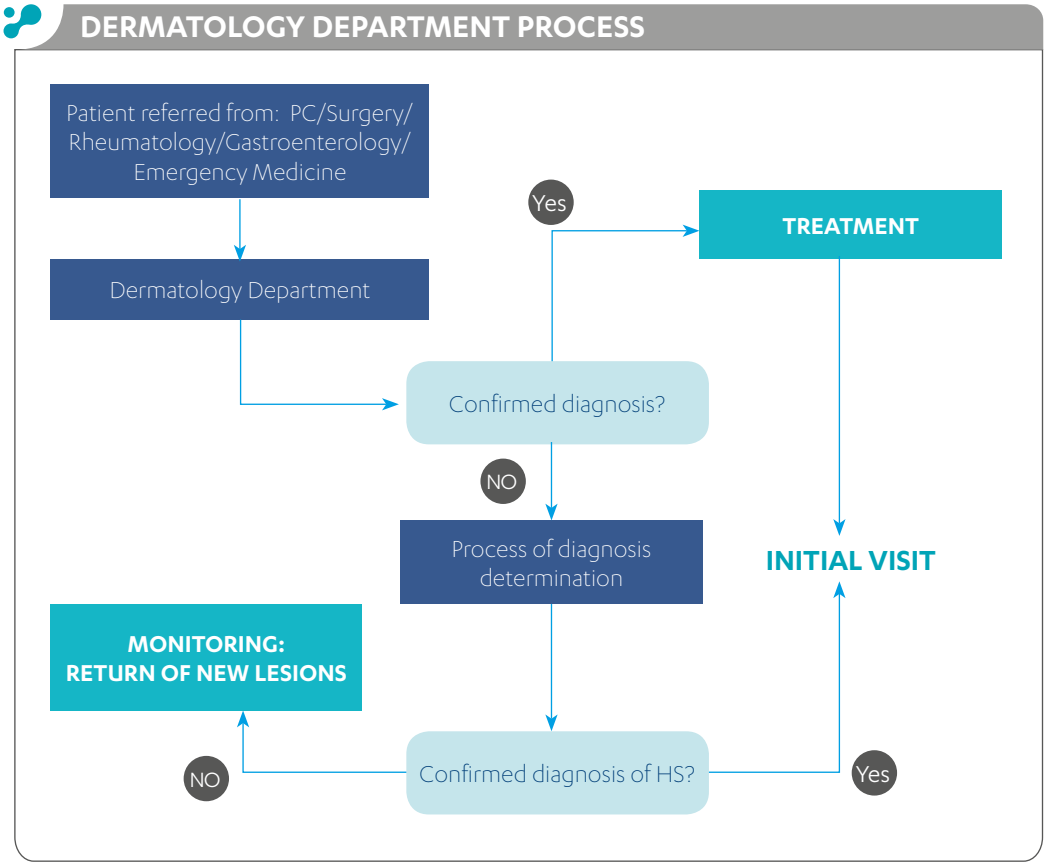
Management of HS in a dermatology department

There are essentially 4 gateways to dermatology for a patient already diagnosed with HS or legitimately suspected HS: PC, surgery, gastroenterology and rheumatology. If emergency reference offices (see Chapter 10) are implemented, emergency departments would become the fifth gateway for a patient with HS or an uncertain diagnosis of HS.

According to the data provided by the HS unit of the dermatology department at Hospital de Manises, 50% of patients are referred from PC, 30% are referred from surgery and the remaining 20% are equally divided between gastroenterology and rheumatology.

The patient who arrives at dermatology may be seeking treatment, a diagnosis or a confirmed diagnosis.

Figure 19. Management of the patient in dermatology.



The initial visit

Once there is diagnostic confirmation, the physician and the nursing staff will perform a visit that must include the following assessments, examinations and tests:

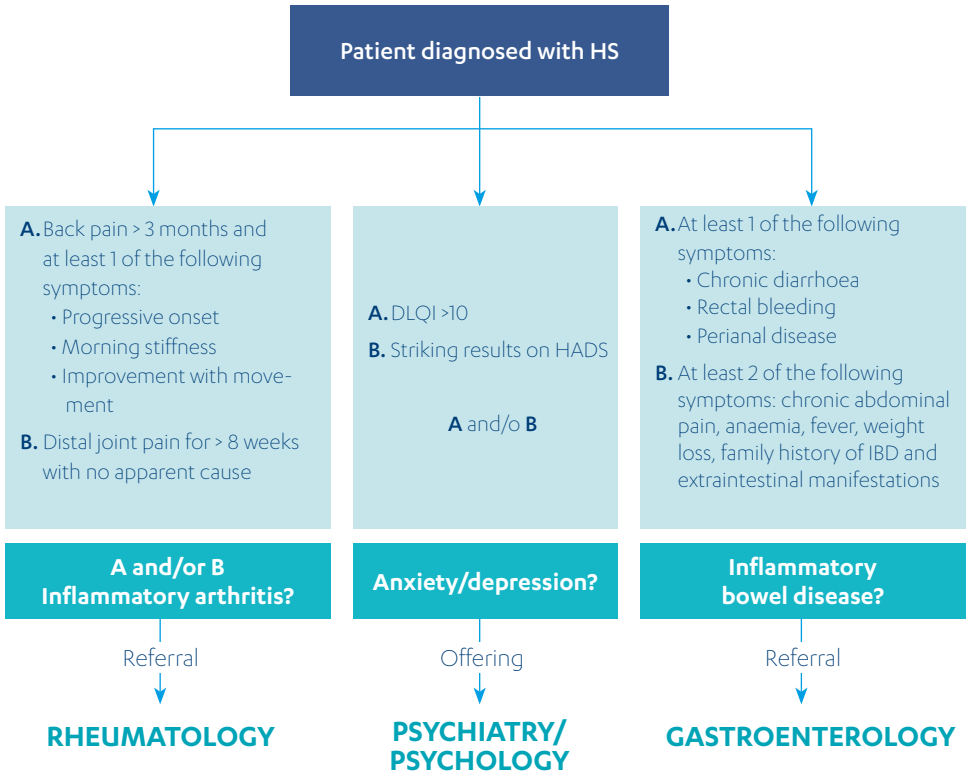
INITIAL VISIT

- **Explanation of the disease**: description, type of lesion, prognosis and expected course, general outbreak prevention measures, etc.
- **Clinical assessment** including collection of general information such as weight, blood pressure, waist circumference and body mass index.
- **Physical examination** of lesions in commonly affected areas including examination using ultrasound technology.
- **Classification of the patient** according to seriousness using the Hurley scale and the HS-PGA classification.
- **Assessment of impairment** of quality of life using the *Disease Life Quality Index* (DLQI).
- **Assessment of comorbidities** associated with HS. With regard to psychological affection, is broadly addressed in the chapter "Comorbidities associated with HS, Psychological and social intervention" in this document. Digestive comorbidities are included in the chapter "comorbidities associated with HS: inflammatory bowel disease".

  In any case, a protocol for suspicion and referral of patients from dermatology to other specialities if the presence of other diseases associated with HS is suspected is proposed below.
- **Prescribe treatment** based on the stage of the disease and the lesions that the patient has (see Chapters 9 and 14): Indicate complementary testing if required.
- **Give an appointment** for a follow-up visit
  - Hurley stage I patients: Monitoring every 6 months
  - Hurley stage II-III patients: Monitoring every 3 months

Figure 20

Protocol for detection and referral of diseases associated with HS from dermatology



Successive or monitoring visits

Monitoring visits, scheduled as indicated in the previous point for each stage of the disease, would include the following assessments:

MONITORING VISITS

- **Physical examination** with assessment of the lesions using an ultrasound test (see specific section at the end of the chapter) .
- **Assessment of treatment response**. This will essentially be performed using three parameters:
  - The onset or lack of onset of new painful episodes .
  - The DLQI quality of life survey and any changes in score compared to the previous visit.
  - Measurement of results with respect to the Hidradenitis Suppurativa Clinical Response (HiSCR) assessment.

  The meaning of "**patient who does not respond to treatment**" is based on HiSCR:

  - **Patient who does not achieve the HiSCR parameter**, i.e. who does not have a ≥ 50% reduction in inflammatory lesion count (sum of abscesses and inflammatory nodules [AN]), with no increase in the number of abscesses or draining fistulas compared to the baseline situation.
  - Depending on the type of treatment, the cut-off point for assessing therapeutic response ranges from 10 weeks, for combination therapy with rifampicin 600 mg/day and clindamycin 600 mg/day, to 12/24 weeks, for therapy with adalimumab at the dose for hidradenitis suppurativa.
- **Clinical assessment** including collection of general information such as weight, blood pressure, waist circumference and body mass index
- **Active listening** to the patient to collect his or her questions and concerns
- **Treatment**: prescription of extra treatments if required
- **Reassessment** of comorbidities
- **Scheduling of an appointment** for the next monitoring visit.

The nursing visit

As indicated in the chapter on the management of HS by primary care teams, the nursing professional plays a very important role in the management and follow-up of this type of chronic patient, with a disease that involves pain and very severe impairment of his or her social and daily life.

Therefore, the patient should have a scheduled visit with the nursing professional for each scheduled visit with the dermatologist.

To be able to provide personalised care for all patients and cover their different needs, it would be desirable for dermatology departments to have at least one assigned nursing professional specialised in the unique features of dermatological disease.

Objectives of specialised nursing care in HS

- To optimise the dermatology office that cares for patients with HS
- To provide individualised care specialised in HS, specifically dressing of complex wounds in patients with moderate to serious HS
- To educate the patient on self-care of wounds and provide the information required or refer the patient to the nursing office at his or her health centre
- To facilitate quick access to dermatology departments through emergency visits, telephone calls or emails
- To educate the patient on HS and answer questions about the disease, treatment, tests to be performed, vaccine status, etc.

DERMATOLOGY NURSING VISIT: PROTOCOL

Initial visit

1. Clinical assessment of the patient: medical history and physical examination.

The keys to active listening should be used in an attempt to create a suitable atmosphere of trust for the patient to express uncertainties and fears.

- Test and scales that should be used at the initial visit:
  - Disease Life Quality Index (DLQI).
  - Visual analogue scale (VAS) for pain and pruritus
  - Hospital Anxiety Depression Scale (HADS) only if the patient is deeply affected and agrees on the need to assess his or her mood.
- Collection and recording in the patient record of static and dynamic data.

Static data (collected at the initial visit; rarely, these will be modified in some check-up should they change):

- Visit date.
- Identification (include telephone number and email address)
- Date of birth.
- Doctor responsible.
- Main diagnosis (Hurley classification).
- Prior diseases and treatments.
- Prior surgical procedures (especially related to HS).
- Comorbidities.
- Toxic habits (sedentary lifestyle, smoking addiction, alcohol use, etc.)
- Information related to lifestyle and profession.
- Lesion location: On an outline of a human body, mark the location, type and characteristics of each lesion (active or residual, scars or fistulas, etc.) and record them with a number (example: Armpit 0 Buttocks 2)
-

Dynamic data (to be taken in each check-up):

- Visit date.
- Anthropometric measures and vital signs:
  - Weight
  - Height
  - Body mass index (BMI)
  - Waist circumference
  - Blood pressure (BP)
  - Heart rate (HR)

- Physical examination and medical history:
  - Review of prior lesions and identification of new lesions.
  - Staging of the disease according to the Hurley scale and HS-PGA.
  - Grading of exudate (X = little, XX = moderate, XXX = abundant).
  - Problems that HS causes the patient (in terms of mobility, foul odour, etc.).
  - Number of outbreaks since the previous visit and severity.
- Test: VAS (pruritus and pain), HiSCR, DLQI, HADS.
- Treatment.
  - Record the treatment (topical or systemic) and the regimen that the patient is following as well as the last dose administered.
  - If the patient is being treated with biologic therapy:
    - Review the rules for storage of the medicine and the technique for administration with the patient. To the extent possible, give an appointment on the day the patient is to administer the medicine, to observe his or her technique.
    - Record the data noted down by the patient in his or her calendar.
    - Obtain the medicine pick-up date (provided by the hospital pharmacy department in the corresponding software application).

2. Find out what the patient knows about the disease and provide verbal information on it in addition to the corresponding information leaflet.

It is recommended that a manageable, simple, visually appealing and easy-to-understand information leaflet be prepared and made available in both physical and electronic formats in all dermatology departments and on the websites of the scientific associations related to the disease. This leaflet may be the same as that mentioned above in the chapter on the management of HS. In any case, it should include the following information:

- Information on the disease (definition, explanation of Hurley stages, etc.).
- Hygiene rules (soaps, methods of hair removal, etc.) and healthy living habits (obesity, smoking, etc.).
- Sources of information and advice (recommended medical websites, patient associations, etc.).
- Contact details for the nursing department (telephone and email), should the patient wish to ask a question or have an emergency.

3. Offer information on general hygiene care and identify risk factors, triggering factors aggravating factors in which it is possible to intervene:
   - **Weight management.** This is an aggravating factor. The patient must be advised to avoid excess weight: advise physical exercise, suggest small dietary changes and refer the patient to a nutritionist if deemed appropriate.
   - **Smoking habit.** The patient must be told to stop smoking or at least smoke less.
   - **Hygiene measures.** Patients tend to bathe in excess, driven by the foul odour that their lesions give off. However, this is not the most beneficial practice for them. The patient must be told not to bathe more than two times per day, and to do so with gentle soaps and without scrubbing. Rarely, the use of antiseptic soaps with miconazole may be recommended. The use of deodorants should be discouraged, since they exacerbate the disease.
   - **Hair removal.** It is believed that this in itself could have the same therapeutic effects for HS, more if it is performed with a laser, due to its anti-inflammatory effect. Therefore, any patient who engages in hair removal must be advised to do so with a laser and be warned of the irritation that shaving and depilatory creams may cause.
   - **Tight clothing.** This is a triggering factor for HS. Therefore, the patient should be advised not to use clothing that may get into their body folds or promote maceration, and instead to dress in loose, preferably cotton clothing.
4. Perform wound-dressing and teach the patient how to do this. Give the patient instructions in writing on how the required wound-dressing should be done.

   It is a good idea to use standardised templates on which nursing staff will record, directly and comprehensibly, the instructions that are most appropriate for each patient: location and type of lesions, material needed and technique for application. This will facilitate healthcare continuity, as the patient may present these instructions at his or her primary care centres. As indicated, the standard of care established for each type of lesion is presented in Annex I.

Monitoring or follow-up visit

At each nursing visit, the patient should be given an appointment for the next follow-up visit with the nursing professional. The recommended frequencies of nursing visits are as follows:

- Patient with serious or Hurley stage III disease: every month.
- Patient with moderate or Hurley stage II disease: every month and a half.
- Patient with mild or Hurley stage I disease: every 3 to 6 months.

If the disease is being treated with biologic therapy, it is advisable to have the date on which the drug is picked up at the pharmacy coincide with the follow-up visit in the dermatology nursing department to facilitate treatment adherence management and treatment administration success.

At monitoring visits, the nursing professional must:

- Assess the course of the disease. Perform an examination and medical history for continuity (assess whether any changes have occurred; whether new lesions have appeared or existing lesions have changed; and whether there is any discharge, foul odour or limited mobility due to retractile scars).

  Perform the following tests:

  - At all follow-up visits: DLQI, VAS (pruritus and pain), HS-PGA and Hi-SCR.
  - At the first follow-up visit and, depending on the results and course, all other follow-up visits: HADS.
- Gather dynamic data from the patient's record. Modify any static data that have changed.
- Assess treatment adherence, potential side effects and the course of the disease.
- Find out whether the patient has read the information provided in writing at the previous visit and whether he or she has any questions. Also find out about any changes in the patient's living habits with questions on whether he or she has stopped smoking or started a diet.

Emergency visit

- Focus the medical history on the reason for the visit.
  - Identify the main symptom (new lesions, pain, pruritus, exudate, etc.).
  - Identify the potential triggering factor (lack of treatment adherence, menstruation, medicines administered for another disease, change in habits, etc.).
  - Scales: VAS (pain and pruritus) and DLQI.
- Refer to the dermatologist if the outbreak cannot be managed with nursing interventions or the triggering factor requires a medical visit.

Coordination and healthcare continuity

Management in the continuity of care of the chronic patient represents one of the most significant challenges currently faced by healthcare systems.

Comprehensive healthcare management is already a reality in many of the regional health systems that comprise the Spanish National Health System, and many Spanish Autonomous Communities have adopted the Figure of a case manager, generally assumed by nursing professionals acting as a case manager nurse or liaison nurse.

HS, in its most severe cases, is a disease that requires a comprehensive, multidisciplinary approach.

Given the characteristics of the disease in cases classified as serious that cause the patient significant episodes of pain, which greatly affects the daily life of the patient and may become debilitating, the patient will require multiple healthcare resources from different specialists throughout life.

These patients require quick access to the healthcare system and receive healthcare from teams in primary care as well as dermatology, emergency medicine, general surgery and/or cosmetic surgery. These patients also sometimes require psychological and/or psychiatric support and/or intervention, as well as specific follow-up by the nursing professional concerning care, self-care, promotion of healthy living habits and therapeutic education.

Therefore, it is considered advisable to generalise the implementation of a nursing visit for these patients in dermatology departments, such that the nursing professional not only performs out specific healthcare tasks, but also acts as a nexus of communication and coordination and facilitates continuity of care between the different professionals involved in the healthcare process of patients with HS in Hurley stage II/III.

This nursing professional would be the referent for the patient and the nurse for consultation on care and self-care for both patients and carers. He or she would act, in effect, as a case manager.

The role of ultrasound

In HS, physical examination may be non-objective in a way, and may underestimate the seriousness and anatomical impairment of the lesions.

In recent years, skin ultrasound has been proven as a technique that, when performed by a dermatologist or a suitably trained radiologist,

- enables real staging as well as dynamic monitoring of the inflammatory activity of the disease, thereby improving its management.

The results obtained by Wortsman et al.[70] based on the authors' own studies intended to comparatively analyse clinical staging and ultrasound of the patient with HS allowed a number of significant conclusions for its management to be drawn.

These authors were the first to report that ultrasound often allows subclinical anatomical changes in the patient with HS to be visualised. The study was conducted in 34 patients with 142 lesion areas, and consisted of comparing Hurley clinical staging to the authors' own system based on ultrasound results (Wortsman's sonographic scoring of hidradenitis suppurativa [SOS-HS]). The areas examined included the armpits and groin in all cases, plus symptomatic areas. The ultrasound assessment revealed subclinical fluid collections in 76.4% of patients, fistula tracts in 29.4%, dermal pseudocysts in 70.6% and enlargement of the hair follicles in 100%. In these cases, the ultrasound examination led to changes in the management of 28 patients (82%) including the addition of antibiotics, immunosuppressive therapies and biologic treatments, as well as the establishment of a surgical approach in 8 cases (24%). Based on this study, Wortsman et al. established the first ultrasound classification of HS, which appears in the table below.

Table 6: Ultrasound classification of HS according to Wortsman et al.[70]

	Hurley	SOS-HS
I	1 or more abscesses with no formation of fistulas or scars	Fluid collection and dermal changes affecting one body area (unilateral or bilateral) with no fistula tracts.
II	Recurrence of multiple abscesses or fistulas and scars in widely separated areas	2 or more fluid collections or a fistula tract affecting more than two body segments (unilateral or bilateral)
III	Multiple abscesses connected by fistula tracts affecting an entire area	5 or more fluid collections or 2 or more fistulas with dermal changes or affecting 3 or more body segments (unilateral or bilateral)

Martorell et al.[71] conducted a study in which they clinically and sonographically assessed a total of 51 patients with HS to analyse the presence of differences in disease staging systems when ultrasound assessment was introduced. It was believed that the lesion clinically classified as a nodule corresponded to the ultrasound image of a pseudocyst. Similarly, the basic lesions, abscess and fistula, were classified by ultrasound with their homonyms fluid collection and ultrasound fistula, respectively. (Figure 19).

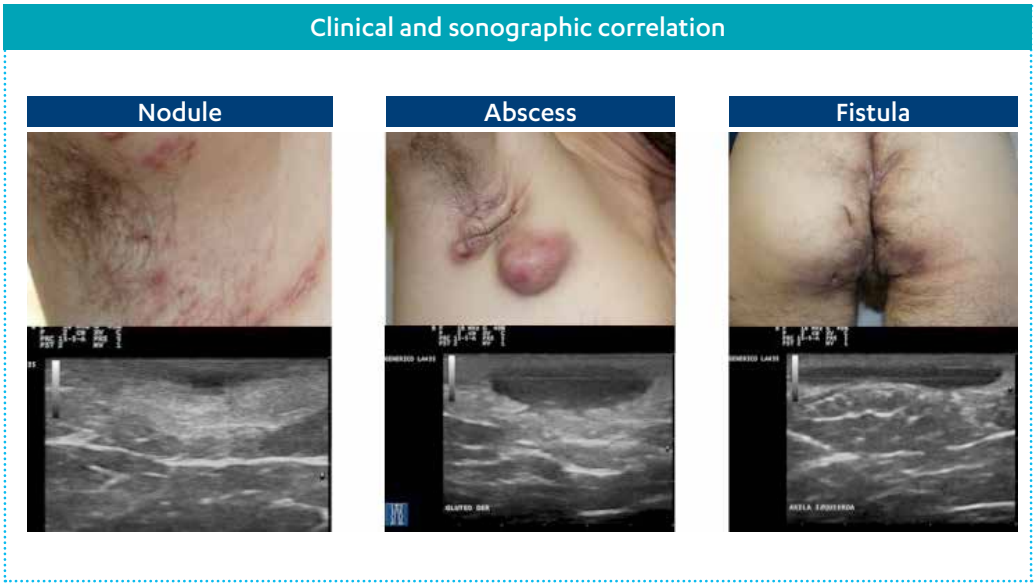
The results obtained were very significant. The clinical assessment of the patient significantly underestimated the degree of severity of HS.

This same group[71] analysed 36 patients with HS with a total of 57 lesion areas using clinical and ultrasound techniques to evaluate the importance of adding ultrasound to assess subclinical disease as well as its staging and subsequent management. This study, like previous studies, found underestimation in the Hurley classification compared to the SOS-HS classification, spe-

cifically in 22% of patients. In addition, the management of 25% of patients was changed from medical to surgical following ultrasound. This Figure was similar to that in the above-mentioned study by Wortsman.

Based on the results indicated, it may be concluded that physical examination in isolation underestimates the seriousness of a significant percentage of patients with HS. Therefore, ultrasound assessment is indispensable for performing an actual assessment of the patient with HS. This staging will be key to establishing suitable treatment.

Figure 21: Clinical and sonographic correlation of HS lesions



(Source: Antonio Martorell).

Monitoring of therapeutic response

The clinical monitoring currently accepted by consensus is defined as Hidradenitis Suppurativa Clinical Response (HiSCR)[72].

Previous sections have already specified that HiSCR is defined as a ≥ 50% reduction in inflammatory lesion count (sum of abscesses and inflammatory nodules), with no increase in the number of abscesses or draining fistulas compared to the baseline situation.

Therefore, HiSCR is a clinical objective based on the total count of inflammatory lesions in an affected patient at a given time.

This parameter is useful in measuring medical treatment response. However, due to the reasons previously discussed, clinical assessment is insufficient as it is not possible to establish the number and actual activity of the lesions of the patient being examined

Therefore, ultrasound becomes a tool that allows the monitoring of the patient with HS to be improved.

PROTOCOL FOR ULTRASOUND MONITORING[70]

- Skin ultrasound on the patient with HS should be performed according to these steps:
  - Surface of the armpits and groin.
  - Areas with clinically evident lesions. In these cases, ultrasound will allow the actual extent and subtype of the lesion observed to be established.
  - Symptomatic areas. Those areas not clinically affected but with symptoms such as pain or itching often hide underlying lesions that account for the signs and symptoms.
- According to the diagram, the follow-up report for the patient with HS should include the following parameters, recorded by area affected:
  - Number of pseudocyst nodules (clinically corresponding to nodules), fluid collections (clinically corresponding to abscesses) and fistulas.
  - Anatomical location of the lesions: dermal, hypodermal, other.
  - Size of the lesions. The major, minor and transverse axes will be collected.
  - Doppler activity in the area being examined. This is a dynamic parameter that reflects an increase in the vascularisation of an anatomical area which allows inflammatory activity to be monitored. It also confirms the active state of the disease in this area. This parameter is very sensitive to therapeutic response.

Ultrasound and surgery in HS

In situations in which a surgical procedure is proposed, either due to medical treatment failure or to optimise the management of inflammation, delimiting the area to be removed represents another therapeutic challenge.

Clinically, the typical situation consists of unstructured skin with areas of inflammation and scars. This makes it complicated to discern between healthy skin and diseased skin. In addition, fistula tracts, which are often multiple, usually cannot be seen under direct visualisation, and as a result procedures are not as effective as they might be.

Skin ultrasound is a quick tool that may be used preoperatively for better delimitation in a procedure in HS. This is based on the technique's capacity for detecting differences between healthy tissue and tissue affected by the disease.

In many cases, especially with moderate and severe HS, extensive surgery leads to a reduction in disease activity resulting from a decrease in the inflammatory burden. However, relapse is relatively common in cases of surgical treatment in isolation.

In these cases, clinical assessment allows us to suspect the presence of relapse due to the onset of discomfort in the form of pain or itching in the area treated. However, without a complementary imaging test, it is often impossible to distinguish between a relapse and the symptoms of postoperative healing itself.

Ultrasound, through the detection of ultrasound structures typical of HS, which are intermingled with bundles of fibrosis secondary to surgery, and through the detection of Doppler activity, an indirect sign of active inflammation, allows a relapse to be detected early, which in turn allows effective medical or surgical treatment to be started.

Reference centres, departments and units (RCDUs)

The Spanish National Health System includes reference units for diseases whose care must be centralised in a number of centres due to either their low prevalence or the specificity of the resources demanded by said care. These centres have the professionals, technology and (in general) resources needed to optimise their care and treatment and, at the same time, gather information and knowledge on the disease to promote research on them.

As indicated in Spanish Royal Decree 1302/2006[73], the designation of reference centres, departments and units (RCDUs) is intended to:

- Improve equity in access to departments with a high level of specialisation by all citizens when they require it.

- Consolidate highly specialised experience, thereby ensuring high-quality, safe and efficient healthcare.
- Improve the care of diseases and procedures with a low prevalence.

Based on this definition, a distinction may be made between reference centres and reference departments.

A reference centre is a centre essentially dedicated to caring for certain diseases or groups of diseases with one or more of the characteristics defined in the Spanish Royal Decree mentioned.

A reference department is a department dedicated to using a technique, technology or procedure or to caring for certain diseases or groups of diseases with one or more of the characteristics set out in Spanish Royal Decree 1302/2006, in addition to caring for other diseases for which that department is not considered a reference department.

Specifically, the diseases likely to have reference centres or departments, as indicated in the Spanish Royal Decree cited, are as follows:

- Diseases whose prevention, diagnosis or treatment requires a special technique or technology that in turn requires a high level of specialisation or experience.
- Diseases whose diagnosis or treatment requires the use of a technology that in terms of cost–effectiveness requires a certain concentration of patients to achieve a minimum number of cases.
- Diseases considered rare for which the reference centre or service is a comprehensive reference point for the patient or acts as a consultant for other healthcare centres.

To achieve the designation of reference centre or department, the knowledge, experience and technology of a centre or department should be accredited and it should have all the human and technical resources needed to provide optimal patient care.

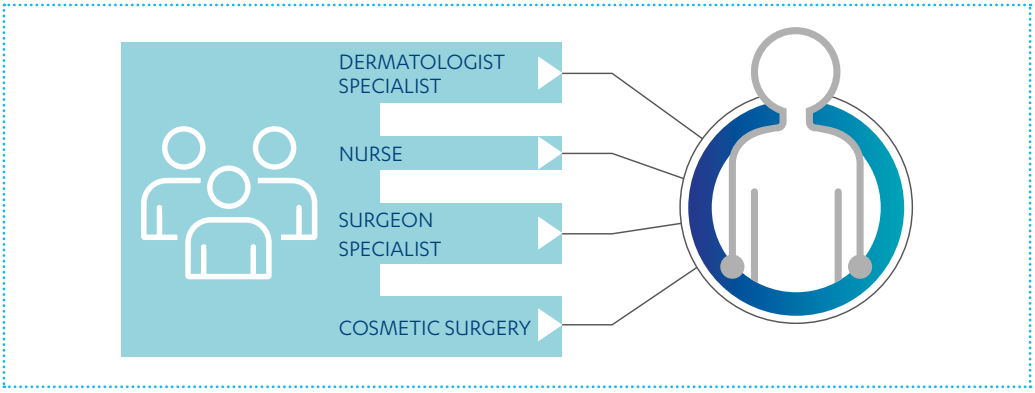
Any patient in the Spanish National Health System is entitled to care at the reference centre or department for his or her disease.

HS reference units?

Some countries around Spain differ from it in that they have reference departments or units for the care of HS: Germany, Italy, France, the United Kingdom and the Nordic countries.

As indicated in this document and the references consulted and referred to herein, HS requires comprehensive, multidisciplinary care. The management of a patient with HS, especially in the most serious cases, requires the intervention of different disciplines and different healthcare professionals.

Therefore, it could be said that the patient has some specific needs to be covered by a comprehensive, multidisciplinary group — ideally, a dermatologist specialising in HS; a nurse with specific training for therapeutic patient education tasks, provision of care and adjuvant psychological support; a surgeon specialised in general colorectal surgery or cosmetic surgery with experience in chronic inflammatory disease — and, at the same time, requires quick access to dermatological emergency medicine.



On the other hand, the fact that a disease has reference centres or units represents a push for research on this disease and enables participation in European programmes that seek to establish networks of collaboration among researchers on a European level, as is the case of the European Cooperation in Science and Technology (COST) project; access to European Reference Networks (ERNs), vehicles for pooling knowledge on the diseases and innovations around them; promotion of training and research; and improvement of patient access to equitable healthcare.

However, despite the complexity of achieving a standard of care for the patient with HS and the ambiguity that currently surrounds the protocols for the management and referral of these patients, as indicated throughout the document, HS is diagnosed clinically and therefore requires no specific technology.

As indicated in the chapter on the epidemiological aspects of the disease, the prevalence of HS is around 1%, depending on the study. This is a high prevalence in a way, unlike that of a rare disease, which means that it would not require the designation of a reference unit or department.

Therefore, at present, it is hard to believe that within the current legislative framework regulating the designation of RCDUs in the Spanish National Health System, HS could be considered a disease that might end up having an RCDU.

However, given the unique features of the disease — which, in its most severe cases, requires intervention by different specialists who must act in a coordinated fashion, and the starting situation in which patients find themselves nowadays, which is characterised by a significant delay in diagnosis as well as a general lack of knowledge on the part of many healthcare professionals

of the disease and its significant implications for the daily lives of patients — it is considered appropriate, and

- recommended by the multidisciplinary team that worked on the preparation of this document, to establish, recognise and spread awareness of the existence of functional reference units, which act as consultants for other departments, mainly dermatology departments, with less experience with and knowledge of HS and course, comorbidities and potential complications.

Is there a need for a clinical guideline?

According to the Spanish Ministry of Health, Social Services and Equality, as indicated on the Spanish GuíaSalud website[74], the recommendation for preparing a clinical practice guideline (CPG) is determined by various reasons, including:

1. Variability in clinical practice due to the presence of areas of uncertainty.
2. Presence of a major health problem with an impact on morbidity and mortality.
3. Development of novel techniques or treatments.
4. Potential for achieving a change to improve outcomes in care because:
   a. The process is likely to be improved by a healthcare intervention.
   b. The means to achieve it are available.
5. Priority area in the Spanish National Health System.

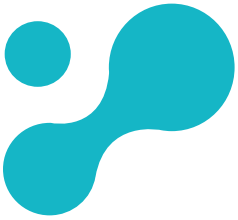
In HS, at least 3 of those reasons coincide: variability in clinical practice due to the presence of areas of uncertainty, development of novel techniques or treatments, and potential for achieving a change to improve outcomes in care.

CPGs are understood to be very useful from both a clinical and an administrative point of view. From a clinical perspective, they help healthcare professionals and patients to make informed decisions when faced with different healthcare options. From an administrative perspective, they serve to support healthcare resource managers and planners in decision-making.

- The expert panel that worked on this document believes that the preparation and implementation of CPGs will undoubtedly improve the effectiveness of interventions and the quality of healthcare in HS.

Recommendations to improve the management of HS patients in dermatology departments

1. **Disseminate HS care protocols in dermatology departments** through the AEDV.
2. **Generate awareness of the standard of care** for HS lesions.
3. Promote the existence of at least **one nursing professional in dermatology departments** who assumes the work of healthcare coordination for serious patients, therapeutic patient education and other tasks described in this document.
4. **Extend the use of ultrasound in dermatology departments** to determine the extent course and response of HS lesions in detail.
5. **Promote healthcare coordination between specialists** (dermatologists, gastroenterologists, rheumatologists, family physicians, etc.) through clinical sessions direct communication, etc.
6. **Generalise the implementation of a nursing visit** for the care of HS patients with staff trained in the care of this disease.
7. **Enhance, recognise and disseminate the presence of functional reference units so that they act as consultants** in the management of complex cases of HS for other dermatology departments in the Spanish National Health System.
8. Promote the implementation of **patient registries** that facilitate follow-up and clinical research.
9. Establish **quick referral pathways** from PC, paediatrics, emergency medicine, surgery and dermatology **to ensure healthcare continuity**.
10. Have the SAs involved **prepare a Clinical Guideline** that compiles the consensuses reached in this document.



Emergency departments and HS

According to the data collected by the HS Barometer published by ASHENDI, during the time it took the patients surveyed to be diagnosed, the healthcare department that they visited most was the emergency department. Specifically, the patients consulted stated that they had visited the emergency department 8.5 times on average, versus the 2 times that they claimed to have visited their GP and the 2.3 times on average that they claimed to have visited their dermatologist.

These data reveal the need to involve in-hospital and out-of-hospital emergency services to achieve an effective, differential approach to HS.

Nowadays, emergency medicine professionals may be the healthcare professionals that see HS the most, although on most occasions it is has not been diagnosed as such.

Therefore, intensive education of emergency departments and dissemination of the protocols and recommendations in this document are necessary key recommendations for intervention.

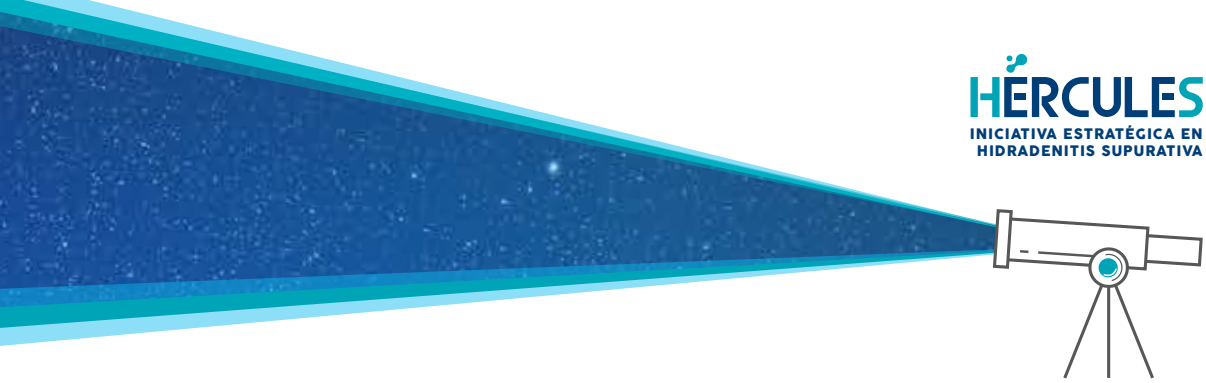
Care of HS in emergency departments

Emergency care is a key element of any healthcare system, and there is a growing interest in increasing the satisfaction of patients and their families or carers with this healthcare setting.

Healthcare quality comprises both the scientific and technical quality of the care received, and the quality perceived by the patient during the healthcare process.

The user's point of view represents one more parameter for assessing any healthcare intervention. User satisfaction should be understood in terms of satisfied expectations and perceived quality.

At this point, it is appropriate to note a piece of information deduced from the HS Barometer: more than 60% of the patients consulted stated that they were unsatisfied or not at all satisfied with the care that they and their family members received from the healthcare system. When they were specifically asked about their satisfaction with the healthcare that they received in relation to HS, more than 72% stated that they were unsatisfied or not at all satisfied.



These Figures clearly contrast with the satisfaction surveys that the different regional health services regularly carry out, which, in general, reflect very high levels of satisfaction.

In Spain, although the public health system has other resources for emergency care, hospital emergency departments represent the most common care level, receiving more than 26 million visits per year, according to the data from the Spanish Ministry of Health[75].

Consistent with the data published by the Spanish Ministry of Health in the healthcare Barometer[76], hospital emergency departments are regularly used by only 16 percent of the population. This assumes that some layers of the population use these departments several times per year, many of them within potential vulnerable groups such as paediatric, multi-disease, elderly, chronic, oncology, palliative-care, rare-disease and psychiatry patients.

Emergency departments constitute not only one of the two gateways to the healthcare system, together with primary care, but also a sort of safety net for the system itself.

As indicated in the introduction to this chapter, HS patients, whether or not they have been diagnosed with HS and regardless of how long they have had the disease, represent one group that has to make recurring use of emergency care.

Diagnosis of HS at in-hospital and out-of-hospital emergency services

As explained in the previous chapters, the diagnosis of HS is eminently clinical. As indicated in the diagnostic algorithm "Diagnosis of HS", visual examination of the lesions and their location and recurrence, together with other minor criteria, are the elements needed to identify HS.

Therefore, it is recommended that the diagnostic algorithm for HS be disseminated at all in-hospital and out-of-hospital emergency services, and that training tools and efforts be implemented for the professionals who work in these departments, both on the key elements for diagnosis — lesions, location and recurrence — and on the generic management of this disease.

An intervention on other levels that directly addresses the difficulty of diagnosing these patients and their dispersion within health systems is recommended. This would involve

- implementing measures that ensure follow-up, or a confirmed diagnosis, when there is potential diagnostic uncertainty concerning lesions suspected a priori of being HS by the emergency medicine professional.

The establishment of **emergency reference or quick consultation offices** may be very useful, as they allow the patient to be quickly referred to dermatology and seen by his or her specialist within a few days.

This type of visit would solve the problem detected by professionals of the difficulty of follow-up of patients who, driven by the need to make a diagnosis or by the search for a solution to painful, relapsing lesions, wander through the healthcare system from one specialist to another without the professional managing to trace an accurate history of the disease which aids in diagnosis and management.

Emergency reference offices would achieve suitable healthcare continuity, once the intervention in the emergency department generally intended to relieve pain has been performed, with a procedure if minor surgery is required. This type of quick consultation could also be extrapolated to other specialities to improve the management of certain diseases in which recurrence is essential for establishing an accurate diagnosis.

Management of HS in emergency departments

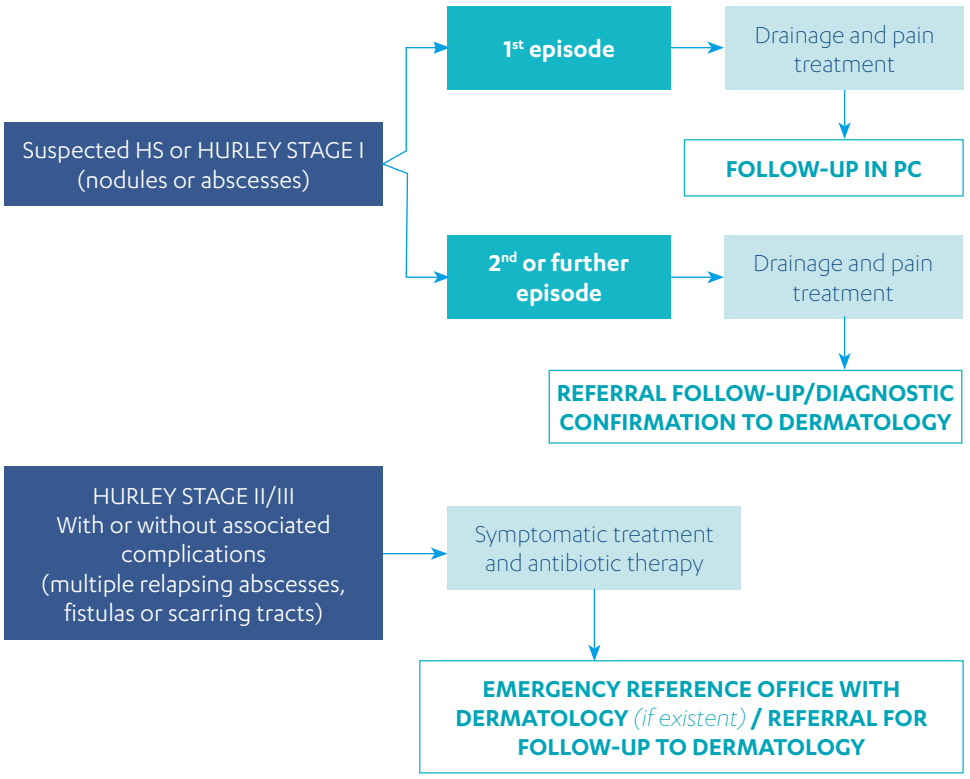
In relation to that explained above, the recommended management by an emergency medicine professional when faced with a patient with HS or with lesions suspected to correspond to HS appears in graphic form below.

For the implementation of that management, it must be stressed that the professional should be familiar with the lesions characteristic of the disease: Hurley stage I, largely follicular nodular lesions or abscesses; Hurley stage II, presence of relapsing abscesses or of fistulas in the characteristic areas; Hurley stage III, multiple abscesses and fistulas.

Based on the classification of the seriousness of the lesions, implementation of the approach appearing in Figure 22 is proposed.

Figure 22.

Management in emergency medicine

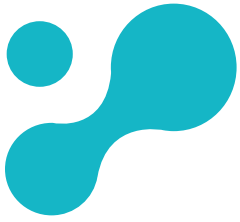


Source: Prepared by the authors based on the contributions made by the expert panel for the strategic health initiative in HS.

Recommendations to be implemented in the care of HS in emergency departments

1. **Disseminate the diagnostic algorithm for HS** such that all in-hospital and out of-hospital emergency services have access to it.

2. Examine the implementation of **emergency reference or quick consultation offices** so that a patient who has visited an emergency department due to an outbreak or painful episode is seen by the-dermatologist within a few days for diagnostic confirmation, treatment or follow-up of his or her disease.



Surgery for HS: indications, techniques and outcomes

This chapter analyses the indications, preoperative care and surgical options for HS.

Before clinical considerations are pinpointed, the need to strengthen healthcare continuity for patients once they must undergo a surgical procedure must be stressed.

As deduced from the HS Barometer and from the personal experience of the experts who participated in this consensus, the healthcare continuum for the patient, the traceability of the patient's disease, the follow-up performed by the patient's medical team of his or her disease, etc. break down at this point.

Following surgery, many patients do not return to their dermatologist for monitoring, their PC team loses track of them and they cease to have a reference within the system for the management of their disease.

This, combined with the high degree of relapses that occur following the procedure for the lesions, causes the patient to wander through the system without monitoring, care or treatment suitable for his or her disease.

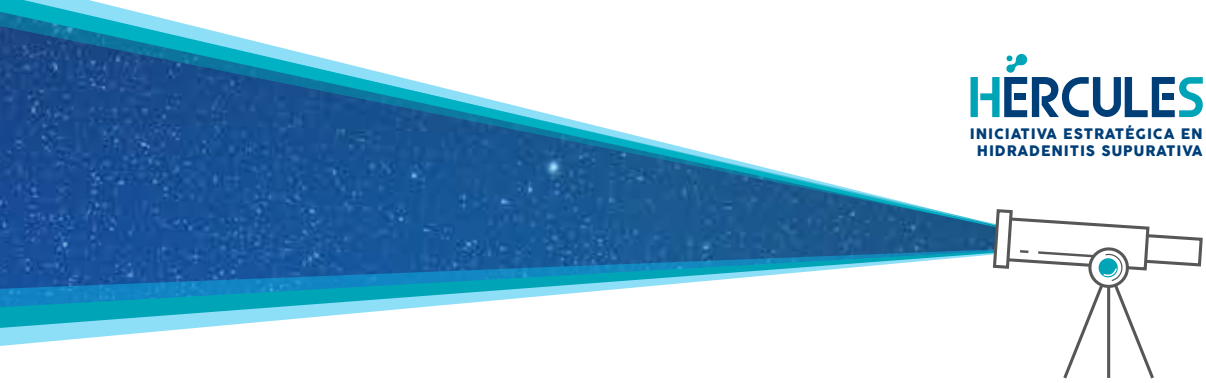
Surgical planning

Preoperative care

As a general rule, at present, complete management or at least a reduction in inflammation is recommended prior to surgery in any patient with HS with active disease.

In mild and moderate cases, a cycle of antibiotics for 10-12 weeks, usually rifampicin 300 mg every 12 hours plus clindamycin 300 mg every 12 hours, may suffice. In more serious cases, prednisone may be added at doses of 1 mg/kg during a short cycle for 3 days, with a subsequent drop in 10-14 days. In patients who do not respond, adding a TNF-alpha inhibitor, in this case adalimumab (160 mg in Week 0, 80 mg in Week 2 and then a weekly dose starting from Week 4 [40 mg weekly]) in the preoperative period allows the management of inflammation needed to obtain a better surgical outcome to be achieved[47,49,52].

Another basic key point for achieving an optimal surgical outcome is smoking cessation. The negative effects of nicotine on tissue regeneration in the surgical bed have been widely demonstrated. Therefore, prior to surgery, it is advisable to offer these patients smoking cessation pro-



grammes to get them to stop smoking or at least drastically limit their nicotine consumption and thus achieve the desired surgical outcome.

Anaesthetic preparation

The choice of the anaesthetic procedure will depend on the extent of the lesions and the depth of the procedures.

- Local anaesthesia:
  - Indicated for small lesions in any location.
  - An anaesthetic mixture of lidocaine 1% (1 amp. 10 ml = 100 mg) + 0.8 M bicarbonate (1 part bicarbonate per 9 parts lidocaine) may be used, bearing in mind that the maximum recommended dose of lidocaine is 5 mg/kg of patient body weighte.
  - Adrenaline may be added to the mix, but it should first be diluted to concentrations of 1:100,000. In this case, the maximum dose of lidocaine may be up to 10 mg/kg of patient body weight. Some authors have defended the use of maximum doses as high as 35 mg/kg when combined with adrenaline.
  - It should be kept in mind that local anaesthesia administered in an inflamed area is absorbed to a greater extent than local anaesthesia administered in healthy skin, and so the patient should be monitored for the onset of early signs of lidocaine toxicity, such as metallic taste, tremor, seizure and loss of consciousness.
- Tumescent local anaesthesia:
  - Indicated for extensive lesions on the upper arms and legs.
  - The same precautions for dosage and clinical monitoring that apply to local anaesthesia should be taken.
  - Klein's solution may be used by adding the maximum safe dose of lidocaine to a 1000-ml normal saline solution containing one ampoule of bicarbonate and one ampoule of adrenaline.
  - Usually, the anaesthesia is injected by mechanical means and efforts are made to skirt the lesions without penetrating them until induration of the subcutaneous tissue has been achieved. The speed of injection should be adjusted to the tolerance of the patient, preferably slowly.

- After the anaesthesia has been injected, it should be given 10 to 15 minutes to take effect. Its effect continues after the procedure.

- General anaesthesia and spinal block:
  - Indicated for large lesions that affect the area around the ears, armpits, groin and perianal area.

Surgical options[49,77-80]

Surgery is indicated in isolated nodules and fistulas, and in extensive, severe cases that do not respond to medical treatment[49]. There are multiple surgical techniques: incision and drainage, *deroofing* and marsupialisation, localised removal, and extensive removal.

The type of surgery and margins will be selected based on the area and degree of impairment.

- **Incision and drainage.** This is a simple procedure that may be performed at the office under local anaesthesia and tends to cause rapid relief of the pain of isolated nodules. However, relapse is the norm. Therefore, its use should be limited to managing pain related to taut abscesses[77]. A modification of this procedure this has been described as "punch debridement": with a circular biopsy of 4-7 mm, a deep incision centred on an inflamed pilosebaceous unit is made, followed by debridement by means of surrounding pressure and subsequent curettage[77-78].
- **Deroofing.** Deroofing and marsupialisation is a simple technique by which, using a probe or mosquito forceps, the fistula tract or the roof of a nodule is transfixed and this tissue is removed using scissors, an electroscalpel or radiofrequency. This exposes the wound bed and allows curettage of the wound to be performed. Subsequently, the lesions heal by secondary intention. This technique is suitable for recurring, painful stage I or II lesions and achieves acceptable cosmetic results. Around 17% of lesions thus treated recur in an average of 4.6 months[49,79]. This is because the technique does not allow the removal of deep epithelial remnants characterised by a gelatinous consistency that could maintain lesions or promote the reappearance of lesions.
- **Local excision.** This has the same advantages and disadvantages as incision and drainage. However, it is useful for removing isolated nodular lesions that do not respond to medical treatment in patients with HS in Hurley stage I and II.
- **Wide excision.** This consists of removing an entire affected area with wide surgical margins, beyond the visible areas. Combined with medical measures and treatments, it is probably the option with the highest probability of achieving management of the disease in patients with chronic, extensive disease in Hurley stage III.

The wound created may be reconstructed by means of simple closure, local or free flaps, grafts, tissue expanders, or simple closure by secondary intention.

Margins between 0.5 cm (armpit) and 1.5 cm are advised. Deep excision as far as the fascia or at least 5 mm of fat is also important to ensure the removal of the deep coils of the apocrine

glands. However, removal with margins does not ensure the absence of recurrence in remote apocrine territories.

Closure of the wound by secondary intention is currently one of the most widely accepted methods given its good medical outcome. However, in this case, time to closure is size-dependent, and it may take up to 3 months to achieve complete healing.

If proceeding to primary wound closure, non-braided monofilament sutures, preferably made of polypropylene, must be used. This is intended to keep from adding inflammation and lytic processes typical of absorbable sutures. The stitches should be tight enough to promote the flow of serum through the wound, thereby preventing the formation of a seroma or the development of a local infection.

Meshed skin grafts may also aid in wound closure and simultaneously allow serous contents to be evacuated from the wound bed. Grafts are easier to use on flat areas, for example when lesions extensively affect the gluteal area.

The use of random flaps such as the closure of the groin by lowering an abdominoplasty flap and the closure of the labia majora by raising medial thigh flaps are techniques used for the closure and recovery of function of large anatomical areas with a residual symptomatic scarring phenomenon.

The choice of closure method and the outcome of the procedure will vary based on the experience of the surgeon and the surgical wound.

Closure of the wound by secondary intention is currently one of the most widely accepted methods, but this procedure is not free from complications, mainly when this closure is used for major skin wounds. This is explained by a higher risk of surgical wound infection as well as by the fact that large wounds closed by means of secondary intention have a higher risk of retraction and residual mobility abnormality if intensive physiotherapy is not performed from the first 24 h following surgery. Therefore, this closure seems to be advisable for closing small wounds.

Although some authors discourage the use of primary closure due a high risk of relapse (54% to 69.9% versus 13% for grafts and 18% for local flaps), such differences are attributed to the higher numbers of affected margins and incomplete resections.

All things considered, the rates of relapse associated with the different reconstruction systems vary widely. It is very difficult to compare different modalities due to the nature of the disease itself and the number of techniques. However, some studies that have assessed rates of relapse based on location have observed that it occurs less often in the armpit (3%) and perianal area (0%) than in the inguinoperineal (37%) and submammary area (50%). This suggests that relapse may be related to the greater extent of apocrine glands in these areas.

The addition of *vacuum-assisted* closure consists of a vacuum system that promotes negative pressure, which heightens blood flow, increases granulation tissue and facilitates wound drainage, thereby decreasing the bacterial load. It has been used in extensive defects and has demonstrated better outcomes and lower rates of relapse.

Table 7: Comparison of results by technique. Adapted from Mehdizadeh A, et al.[80]

Surgical technique	Mean rate of recurrence (%)
Wide excision	13
Primary closure	15
Flap	8
Graft	6
Local excision	22
Deroofing	27

Basis for the assessment of the surgical outcome

It is sometimes difficult to determine the best surgical option, in large part due to differences between patients as well as the clinical variability of the disease. Moreover, while HiSCR is a validated measure of outcome following medical treatment, measures of outcome following a surgical procedure have not yet been defined.

Four measures for the assessment of surgical outcomes have been proposed:

1. **Relapse:** measured as onset of inflammatory activity within 5 mm of the surgical incision.
2. **Time to closure of the surgical wound**, measured in days from the removal of sutures or in days to closure by secondary intention.
3. **Complications**, including aesthetic and functional sequelae.
4. **Patient satisfaction questionnaires**, validated questionnaires being preferable (DLQI, and, to a lesser extent, SF-36 and Rosenberg Self-Esteem Scale)[81].

These 4 elements should be assessed by the professionals who examine the surgical outcome in the patient with HS (surgical dermatologists, coloproctology surgeons, and/or cosmetic surgeons).

Recommendations in the surgical setting

1. Ensure the **continuity of the healthcare process** through suitable postoperative care and coordination with the healthcare team responsible for the follow-up of the patient.

2. Ensure **coordination with in the patient's healthcare team in decisionmaking to minimise the Irreversible Impact of the lesions**.

3. Promote **training efforts** on HS for surgery professionals.

Comorbidities associated with HS: inflammatory bowel disease (IBD)

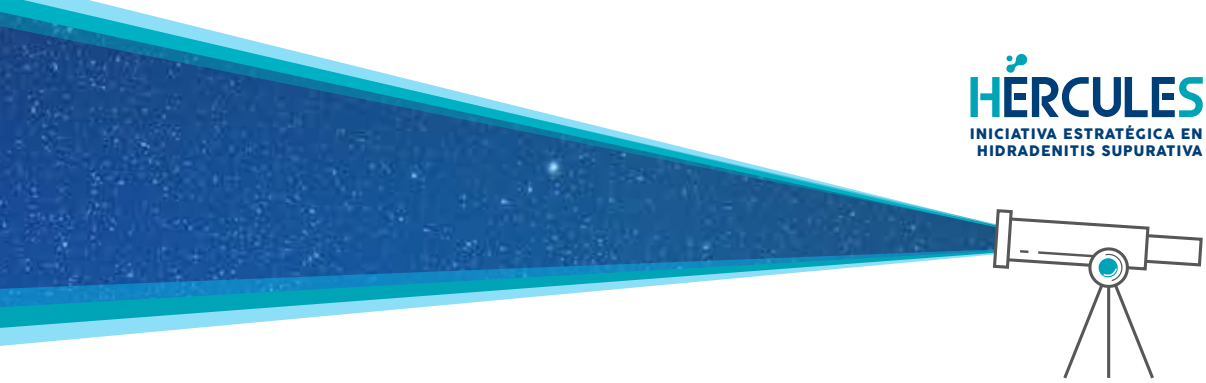
The first studies that assessed the link between HS and IBD (Crohn's disease and ulcerative colitis) attempted to demonstrate that the many cases reported in the literature of HS in patients with IBD could be a result of shared pathophysiological mechanisms, and would explain why they respond to biologic treatments with anti-TNF-α In addition, both diseases are chronic inflammatory processes that affect genetically predisposed individuals, occur at early ages in life and are influenced by shared environmental factors such as smoking.

In recent years, series of patients in different countries confirming the link between HS and IBD have been published. This is especially important given that, in some patients, HS manifests in the gluteal and perianal region and therefore may be mistaken for the perianal variant of IBD and, moreover, patients diagnosed with HS may have gastrointestinal symptoms that should be assessed specifically to confirm or rule out a diagnosis of IBD[82].

This chapter reviews the data supporting the link between the two diseases and establishes recommendations on clinical data causing the clinician to suspect HS in a patient with IBD and vice versa.

Prevalence of HS in patients with IBD

In 2010, van der Zee et al.[20] published the first pilot study in which HS was observed to be present to a significant extent both in Crohn's disease (CD), at 17%, and in ulcerative colitis (UC), at 14%. This study, conducted in 158 patients with IBD, had significant methodological problems which led the authors to presume overdiagnosis. Patients completed a questionnaire with which photographs of typical HS lesions were enclosed and were asked whether they had experienced this type of painful and recurring lesion in the armpits and/or groin. There was no potential for diagnostic certainty. Some patients may have mistakenly identified carbuncles, lymphadenopathy, ectopic Crohn's disease or granuloma inguinale as HS lesions. This same group subsequently published a methodology similar to the prior one, a broader series with 1093 patients diagnosed with IBD (688 diagnosed with CD and 405 diagnosed with UC)[26]. They observed a prevalence of 23% for IBD, 26% for CD and 18% for UC. By severity of HS, 81.5% of patients had Hurley stage I disease and 3.4% had Hurley stage III disease. Both publications[20, 26] concluded that the methodology used limited diagnostic certainty and that studies in which HS was diagnosed by expert dermatologists were needed.



In 2016, the first methodologically rigorous study was published. In this study, the diagnosis was managed and the epidemiological data were contrasted with the general population. This was a retrospective analysis performed in Olmest (Minnesota) in which 679 patients with IBD, diagnosed between 1970 and 2004, were assessed, and cases with diagnostic certainty of HS (biopsies and/or confirmation by a dermatologist) were followed up for an average of 19.8 years[83]. A total of 8 cases with HS were identified (mean age 44.4 ± 8.3 years; 7 women; 6 obese patients). Compared to the general population, the rate of incidence of HS in IBD was 8.9 (IRR) (95% confidence interval [CI]: 3.6-17.5). The cumulative incidence of HS after 10 years was 0.85%, and the cumulative incidence of HS after 30 years was 1.55%. Five patients had CD; 4 of them also had perianal disease. Of the 3 cases with ulcerative colitis, 2 had undergone ileal pouch–anal anastomosis. The study demonstrated that patients with IBD developed HS 9 times more often than the general population, that this increase was observed both in Crohn's disease (CD) (12 times more often) and in ulcerative colitis (7 times more often), and that the predominant phenotype in patients with IBD associated with HS was singular, a perianal phenotype in CD and the need for a colectomy with pouchitis in UC. No significant differences were observed with respect to seriousness of HS in patients with IBD compared to the general population. Female gender and obesity were risk factors for HS.

Janse et al.[84] conducted a study on the prevalence of HS in IBD based on a questionnaire validated for HS sent to 1969 patients diagnosed with IBD at the University of Groningen. Of them, a total of 1260 patients participated in the study, which revealed a significantly higher prevalence of HS compared to the general population (6.8%-10.6% versus 1%-2%). The prevalence was higher in CD (15.14%) compared to UC (6.07%). Patients with IBD associated with HS showed the first symptoms of intestinal inflammation significantly earlier and required anti-TNF-α and surgical resection therapies more often compared to patients with IBD without associated HS. In the multivariate logistic analysis, the risk factors for developing HS in IBD were observed to be female gender (OR: 3.494; 95%CI: 2.138-5.712), CD (OR: 2.112; 95% CI: 1.389-3.213), smoking (OR: 1.910; 95% CI: 1.167-3.126), a high body mass index (OR: 1.035; 95% CI: 1.035-1.118) and, to a modest extent, paediatric ages (OR: 0973; 95% CI: 0.959-0.987).

In summary, it may be concluded that HS is more prevalent in patients with IBD than in the general population; that HS is more prevalent in Crohn's disease compared to ulcerative colitis; and that female gender, overweight, smoking and paediatric ages are independent risk factors for developing HS (in patients with IBD).

Prevalence of IBD in patients with HS

Studies analysing the prevalence of IBD in patients diagnosed with HS have been conducted only very recently. Shalom et al[85] conducted a cross-sectional study in Israel in which they compared the prevalence of IBD in a group of 3207 patients diagnosed with HS at a dermatology centre to a control group of 6412 subjects without HS. A significant association was observed between HS and CD (OR: 2.03; 95% CI: 1.14-3.62), but not between HS and UC (OR: 1.82; 95% CI: 0.81-4.05).

A recently published cross-sectional multi-centre study[86] analysed the diagnosis of IBD made by gastroenterologists using endoscopic/histological criteria in 1076 patients with HS assessed between 2007 and 2015. A prevalence of 3.3% was observed (95% CI: 2.3-4.4). CD accounted for 75% of diagnoses with a prevalence of 2.5% (95% CI: 1.6-3.4), and UC accounted for 25% of cases with a prevalence of 0.8% (95% CI: 0.3-1.4). Among patients with IBD associated with HS, 48.4% had developed HS symptoms before IBD symptoms, 12.9% manifested both processes at the same time and 38.7% expressed symptoms of IBD before HS. When the phenotypic characteristics of HS in patients who had both diseases were compared to the phenotypic characteristics of HS in patients who only had HS, no significant differences were observed. This study concluded that the prevalence of IBD in patients with HS was higher (4-8 times) than that in the general population in the area in which the study was conducted (northern Europe), and that the prevalence of CD would be 8-18 times higher.

In Denmark, a population study was conducted in which all records for residents over 18 years of age were analysed, and the 7,732 patients with a diagnosis of HS were selected and compared to 4,354,137 control subjects[87]. The authors assessed the prevalence of IBD and the risk of developing IBD in both groups. They observed that the prevalence of CD in patients with HS was higher than that in the general population (0.8% vs 0.3%) (OR 2.04; 159-2.62), like that of UC (1.3% vs 0.7%) (OR 1.75; 1.44-2.13). This risk of having CD in a patient with HS was 2.19 (1.44-3.34), and the risk of having UC was 1.63 (1.18-2.27).

In summary, it may be said that the prevalence of IBD in patients with HS is higher than that in the general population, with no differences observed in the phenotypic characteristics of HS between those with IBD and those without IBD. The risk of having IBD is increased in patients with HS.

Diagnosis of HS in patients with IBD

From the data obtained in epidemiological studies, it is deduced that, given that the likelihood of a patient with IBD having HS is higher than that of the general population, the **gastroenterologist must investigate its presence**. Based on the data published to date on risk factors for developing HS in IBD, **special emphasis should be placed on the diagnostic search for HS in patients with CD, female gender, obesity and smoking habit.**

The physician who treats CD in a patient with these characteristics should use the diagnostic algorithm described in Chapter 6 on the diagnosis of HS so as to complete the medical record of the patient with respect to the considerations that said algorithm lists by asking about the clinical condition of the patient both at present and in recent years. The physician must always perform a physical examination of the areas in which the lesions characteristic of HS tend to appear, i.e. the armpits, submammary area, buttocks, genital area and perineum.

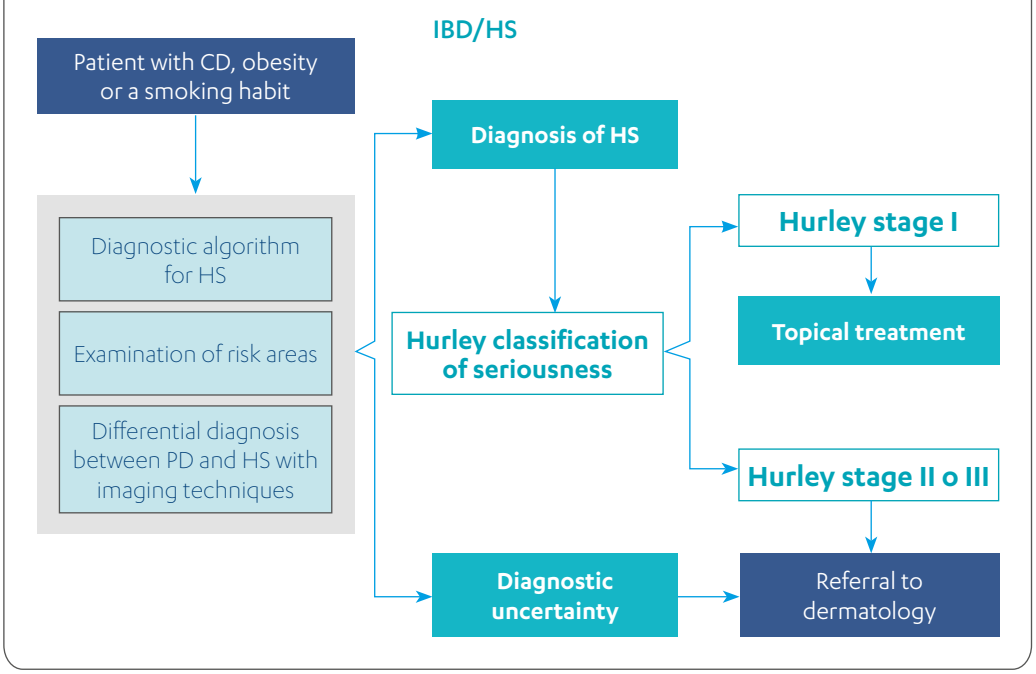
If the patient has perianal or perineal lesions, the use of imaging techniques through ultrasound or magnetic resonance imaging is recommended to be able to make the differential diagnosis between inflammatory perianal disease and HS.

If a diagnosis of HS is confirmed, it is recommended that the severity of the lesion be classified using the Hurley scale. When a patient has Hurley stage II or Hurley stage III disease, he or she must be referred to a dermatologist for assessment and follow-up.

When there is diagnostic uncertainty, or the severity of the disease cannot be classified according to the Hurley scale, it is recommended that the patient be referred to dermatology.

Figure 23.

Diagnosis and management of HS with IBD in IBD offices



*(Martorell82 *).*

Diagnosis of IBD in patients with HS

Given that there are epidemiological data showing a greater presence of IBD in patients with HS, and that the risk of having this disease again is increasing in patients with HS, it is recommended that the presence of potential gastrointestinal inflammatory comorbidities be investigated in the population affected by HS.

To do this, the physician who follows up the patient with HS must establish a series of basic questions and examinations leading him or her to detect the existence of clinical criteria for suspicion.

Recently, a partnership was established between the Spanish Society of Rheumatology (SER), the Spanish Association of Gastroenterology (AEG) and the Spanish Working Group on Crohn's Disease and Ulcerative Colitis (GETECCU) to develop screening criteria based on evidence and expert opinion. This project, called the PIIASER project, is pending publication[88] and proposes some screening criteria for more effective referral between gastroenterologists and rheumatologists to screen patients with associated rheumatic disease or inflammatory bowel disease. The criteria proposed in the PIIASER project for referring patients with spondyloarthritis in whom inflammatory bowel disease is suspected at the gastroenterologist's office may also be assumed for patients suffering from HS according to the expert panel for this strategic initiative. To do this, it is considered appropriate to establish:

MAJOR CRITERIA FOR SUSPECTED IBD IN PATIENTS WITH HS

- Presence of **chronic diarrhoea**, i.e. diarrhoea for more than 4 weeks with organic characteristics. Diarrhoea with organic characteristics will be understood to mean watery diarrhoea or diarrhoea that awakens the patient at night, as well as diarrhoea accompanied by symptoms such as weight loss, fever and signs of malabsorption. It must also be borne in mind that it is associated with extraintestinal manifestations such as rheumatoid arthritis, erythema nodosum, pyoderma gangrenosum, aphthous ulcers and cholangitis.
- **Rectal bleeding**, i.e. bleeding through the anus accompanied or not accompanied by faeces, unless there are very obvious signs of haemorrhoids and haemorrhoids are found on physical examination.
- **Perianal disease** (PD). PD will be understood to be present when patients have a set of lesions that alone or combined appear in the perianal, anal and rectal areas, essentially in patients with CD. These lesions may be the beginning of CD and precede the onset of intestinal symptoms by years. The spectrum of lesions includes: fissures; fistulas; abscesses; skin folds; and perianal maceration, including ulceration.

Any patient who meets at least one of the major criteria described must be referred to a gastroenterologist.

MINOR CRITERIA FOR SUSPECTED IBD IN PATIENTS WITH HS

- **Chronic abdominal pain**, i.e. persistent or relapsing abdominal pain for more than 4 weeks.
- **Iron deficiency anaemia.**
- **Fever or feverishness** without a source.
- Inexplicable **weight loss.**
- **Extraintestinal** manifestations, such as those indicated above, i.e. rheumatoid arthritis, erythema nodosum, pyoderma gangrenosum, aphthous ulcers and cholangitis.
- **Family history** of IBD.

Any patient who meets at least two of the minor criteria described must be referred to a gastroenterologist.

In conclusion, HS and IBD often co-occur. An examination of the axillary and inguinal folds, as well as the gluteal region, will allow cases in which HS is associated with inflammatory bowel disease to be detected early. A meticulous medical history and examination in patients with HS is indispensable for detecting warning signs and symptoms that cause the clinician to investigate the potential presence of IBD. Multidisciplinary management of the patient with both HS and IBD will allow personalised therapy for this type of case to be established and the outcomes achieved to be optimised compared to individualised treatment by each speciality.

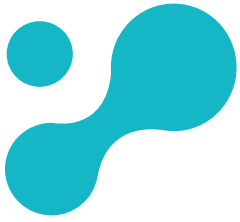
Recommendations to be implemented for early detection of IBD in patients affected by HS and vice versa

1. Distribute an **intervention protocol for early detection of HS in IBD departments that recommends investigating the presence of HS In patients with Crohn's disease, obesity or a smoking habit** by applying the diagnostic algorithm for HS and caring for recurring skin lesions in commonly affected areas.

2. **Disseminate a protocol for diagnosis of IBD in patients with HS** through referral to a gastroenterologist, if at least one of the major criteria is met, or at least two of the minor criteria are met, for suspected IBD.

3. **Promote coordination between gastroenterologists** and dermatologists in the follow-up of the disease.

4. **Promote studies** that analyse the relationship between HS and IBD.



Comorbidities associated with HS: psychological and social intervention

Psychosocial impact

Recently, the impact that HS may have on the mental health and quality of life of patients has begun to be confirmed[89-92]. A decrease in quality of life of up to 60% has been described[93]. Stigmatisation[94], low self-esteem, depression[95,96], irritation, shame, solitude and sexual anxiety are among the psychological, social and emotional difficulties that HS patients have[97].

Health-related quality of life (HRQoL) reflects the subjective assessment made by the patient of the impact of the disease or its treatment on his or her physical, psychological and social well-being[98]. HS has been associated with a significant decrease thereof. Compared to other dermatological diseases, patients with HS have had higher scores (greater impairment) for the same degree of disease severity compared to patients with psoriasis[91,99].

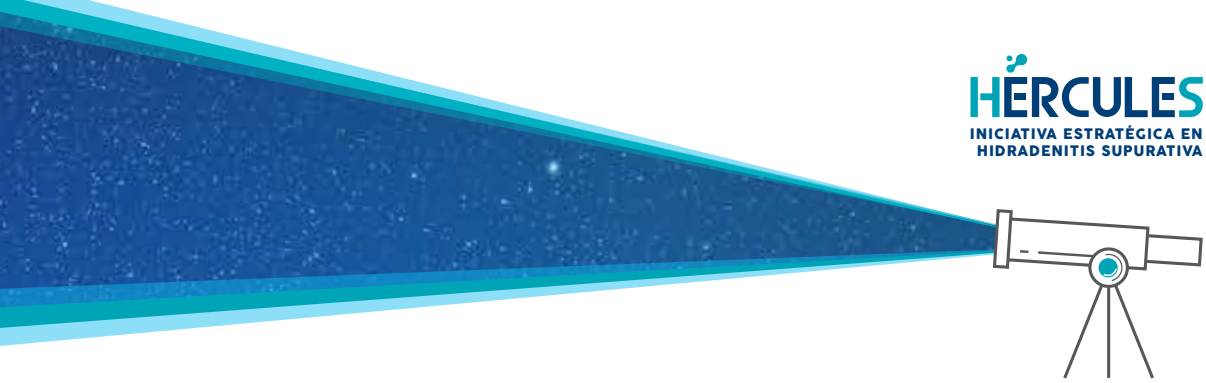
Comorbidities, mental health and quality of life

Chronic diseases may cause changes in the lifestyle of the patient that are potential stressful. When patients with HS undergo surgery, the comorbidities and unhealthy habits that they may have, such as smoking, alcohol use, poor diet and sedentary lifestyle, must be borne in mind.

It is important to detect behaviours and habits that may influence the disease negatively, whether directly, such as smoking, due to the worsening of the disease and the lesions, or indirectly, such as behaviours that manifest in psychological distress: poor eating, sedentary lifestyle, social isolation, etc.[52].

To approach such behaviours and habits, professionals should offer a psychoeducational intervention to inform patients on the risks that certain habits and/or behaviours may present. Some patients will need help to learn certain abilities and acquire the resources needed to lead a healthier lifestyle, especially in accordance with their disease and the limitations present[100].

Some patients may need to be referred to other professionals so that a better assessment and intervention may be performed[101]. Referral to other specialists such as nutritionists, endocrinologists, psychologists and social workers may be very useful for tailoring interventions. Moreover, the patient must be informed of the health programmes available, such as programmes to stop smoking and using alcohol, which may be useful for providing him or her with new abilities and specific resources to manage the disease.



Regarding mental health, some of the most common symptoms that patients with chronic disease tend to have are:

- anxiety
- depression
- stigmatisation
- stress
- irritability
- low self-esteem
- sexual anxietyl[89]

Chapter 1 of this document cited a recent study in which the psychosocial impairment of HS patients was compared to that of patients with COPD, diabetes and oncology diseases.

Some patients with HS perceive social stigma, and this negatively influences their interpersonal relationships. Low self-esteem and sexual anxiety may also influence patients when they are developing relationships, with negative psychosocial repercussions. In addition, personality may modulate the degree of impairment of the patient, especially in those with onset of the disease in adolescence. In addition to all that has been explained, it must be kept in mind that other psychological factors and personal resources may positively or negatively modulate the degree of emotional impairment of the patient.

Modulating psychological factors

Personal coping strategies may influence well-being and quality of life. The patient with positive coping skills will probably have a better quality of life than the patient with negative coping skills. Therefore, it is important to be aware of patients' coping strategies, since this will aid in the management of the disease. In this regard, it would be positive to offer patients training in abilities and resources that allow them to cope more adaptively with the disease. This would predictably promote a better course for the process.

The patient's *beliefs, expectations and values* should be examined, since this information will aid in better understanding the impact of the disease on the patient. This knowledge will allow the different therapeutic options to be offered to the patient to be individualised.

Social support and interpersonal relationships act as modulators that promote the quality of life of the patient with HS. Social support perceived by the patient may influence his or her health. A good social support network, formed through friendships, family members and even social networks, may positively influence health and help to mitigate the negative effects caused by some stressful situations. When the patient is asked about his or her social support networks, both the quality and the quantity of these interpersonal relationships should be kept in mind.

Personality traits are persistent patterns in ways of perceiving, relating to and thinking about one's environment and about oneself that manifest in a wide range of social and personal contexts. According to J.L. Linares[102], "Personality, from the point of view of relationships, is the individual dimension of the cumulative experience of relationships, in dialogue between past and present, and framed by a biological substrate and a cultural context." Thus, the patient's personality will influence the modulators cited above as well as habits and therapeutic adherence.

This may be the most difficult aspect of working with patients, as it is difficult to directly influence their personality. However, it is possible to work on their coping strategies, adjust their beliefs and equip them with resources and abilities so that their way of being interferes as little as possible with their disease following a favourable course.

Special care must be taken with adolescents, since the disease may influence their personal and social development, as well as the formation of their identity and self-esteem.

In conclusion, the personal experiences and life events that patients face should also be borne in mind, since these will positively or negatively influence their beliefs and expectations. Therefore, special care should be taken at specific times in the healthcare process, such as when a diagnosis is made, when test results are received, when examinations are performed, etc., and in particular when there is an exacerbation of the disease, since this may represent greater vulnerability from an emotional point of view.

Psychoeducation in hidradenitis suppurativa

Psychoeducation consists of providing the patient with information on his or her disease and training him or her in different abilities and techniques that may promote well-being. It is a simple tool that is useful for promoting more efficient coping with the disease.

It must be emphasised that education will help to empower the patient in his or her healthcare process. Similarly, educating and training the health professionals involved in the healthcare process will promote professional development tending towards excellence[103-106].

From an operating point of view, it is considered appropriate to distinguish between two different types of psychoeducation in HS: *psychoeducation for professionals and psychoeducation for patients and family members*.

Psychoeducation in HS: professionals

Healthcare professionals, and other professionals that practice their professions in direct contact with patients with HS, should be trained in the physical aspects of the disease (treatment, diagnosis, etc.) as well as its psychological and social aspects. They should also have information on useful resources available for patients.

It is important for the specific field of knowledge of psychodermatology to offer training in its field of expertise on psychological and social considerations associated with HS. This, together with comprehensive knowledge of dermatological disease, will promote more efficient management of the healthcare process.

It may also be interesting to hold clinical training sessions in healthcare settings to promote better knowledge of the psychosocial aspects of the disease, as well as in-person and remote training sessions that facilitate access by professionals to this knowledge.

Psychoeducation in HS: patients and family members

Psychoeducation for patients and family members may be a useful tool that helps them to better understand the disease, take more responsibility for the care needed, be knowledgeable about psychosocial considerations related to the disease and ultimately achieve better health outcomes.

During the visit, healthcare professionals, physicians and nurses, tend to inform patients on their disease and treatment. Healthcare pressure and the little time that professionals have to care for the patient is a disadvantage that may make the healthcare process difficult. The use of written information material that may be provided to patients might mitigate this difficulty in part. (See Annex II.)

Other formats, such as training sessions at hospitals, civic centres and health centres, may be very helpful for broadening the education of patients and family members.

Finally, it is worth noting the great deal of work involved in training, education and promotion of the activities of HS patient associations - in Spain, the Spanish Hidradenitis Suppurativa Patient Association (ASENDHI) (http://asendhi.org/).

Assessment of psychological impact

Some dermatological diseases, such as HS, are chronic, relapsing and/or disfiguring in nature. This may have a negative impact on quality of life and affect the physical, emotional and social well-being of the patient. Therefore, it is advisable to use instruments to assess quality of life and thus determine the impact of the disease on the patient's life[107].

Quality of life should be assessed by two means: on the one hand, a general quality of life assessment using generic instruments such as the Short Form 36-Item Health Survey (SF-36)[108-110] or the EuroQol-5D[111], and, on the other hand, a dermatology-specific quality of life assessment. The most commonly used dermatology-specific quality of life assessments are the Disease Life Quality Index (DLQI)112 and Skindex[113,114].

The former will allow the data obtained in patients with HS to be linked and compared to those obtained with other chronic diseases of other organs or systems. The latter allows a general measure of dermatological quality of life to be performed and quality of life to be compared in patients with HS and other skin diseases. To date, there are no questionnaires or specific instruments for measuring quality of life in HS in Spanish.

The Spanish Psychiatric Dermatology Research Group (GEDEPSI) of the AEDV is working on preparing an instrument to measure quality of life in patients with HS.

Some questionnaires and scales that may be useful in daily clinical practice, as they are easy to administer and interpret, are presented and recommended below.

Dermatology Life Quality Index (DLQI)

Health-related quality of life will be evaluated using the DLQI, a generic instrument for dermatological diseases[112,113]. The cut-off point indicating a poor quality of life is ≥ 10. This is a self-administered questionnaire that requires little time to fill in and correct (Annex III).

Visual analogue scale (VAS) to assess pain, odour and itching

A VAS consists of a line 10 centimetres in length, where the left end of the line represents the absence of the symptom to be assessed and the right end of the line represents the maximum presence of the symptom to be assessed. It is a simple, quick record. The patient should draw a perpendicular line where he or she believes the symptom is located between the two ends. Next, the professional will use a ruler to measure the distance between the left end and the line drawn by the patient. The result obtained with this measurement will be the score that the patient assigns to the symptom assessed. The scores obtained may be interpreted as follows: values > 4: mild, values 4-6: moderate and values > 6: severe. (See Annex IV.)

Hospital Anxiety and Depression Scale (HADS)

The HADS is an instrument for detecting symptoms of anxiety and/or depression. The total score offers a measure of emotional distress. It is a 14-item self-administered questionnaire comprising two 7-item subscales, one for anxiety (odd items) and the other for depression (even items). The items on the anxiety subscale were selected based on analysis and review of

the Hamilton anxiety scale. The inclusion of physical symptoms, which could be confused by the patient with the symptoms of his or her physical disease itself, was avoided. The items on the depression subscale focus on the area of anhedonia (loss of pleasure). The intensity or frequency of the symptom is assessed on a 4-point Likert scale (range 0-3), with different response formulations. The time frame, even when the questions are asked in the present tense, should refer to the prior week. The scoring range is 0-21 for each subscale and 0-42 for the overall score. The cut-off point for potential cases of anxiety and/or depression is > 11. (See Annex V.)

Questionnaire for Psychological Distress in Hidradenitis Suppurativa (CMP-HS)

Finally, a questionnaire specially designed to facilitate assessment in daily clinical practice is proposed. **This questionnaire has not been validated for use in research or clinical trials. Therefore, it is recommended for use only to aid in detecting psychological distress in patients**[115-118].

It is a brief questionnaire administered by the professional in the office to detect whether the patient has difficulty managing emotions and cognitions in the presence of his or her disease. This questionnaire, consisting of 3 open-ended questions, is intended to allow the professional to detect whether the patient has a negative psychological impact and whether he or she requires the help of other professionals to manage this negative impact. (See Annex VI.)

Recommendations

When informing patients of the results of a psychological assessment, it is important to consider the following matters:

1. It is necessary to refrain from labelling people with derogatory terms based on their scores for psychometric instruments.
2. Clear, simple, jargon-free language suitable for each patient in particular should be used.
3. The information obtained must not be conveyed as "gospel truth"; instead, it should be confirmed with the patient. Expressions and questions such as "It seems that", "You may be feeling ... at this time in your life" and "Do you think that this discomfort is caused or increased by your skin disease?" may be used.
4. Positive things should be stressed. The information obtained must not be used to categorise the patient. The results should serve to guide your intervention and help the patient cope with the disease in his or her own way.
5. Whenever the patient confirms significant emotional distress outside of your scope of intervention, referral to a mental health professional may be proposed.

Intervention protocol

The patient with HS may be cared for in different care settings (primary care, specialised care, etc.). These different care settings have different aspects that should be borne in mind. Therefore, specific intervention programmes are proposed within the primary care and specialised care settings.

PRIMARY CARE AREA

- In the primary care environment, physical distress is the first point to bear in mind. Pain may generate irritability in patients and cause both physical and psychological distress. So may itching, odour and other symptoms.
- The following instruments may be useful for assessing the emotional impact of the disease on patients.
  - Visual analogue scales (VAS) to assess pain, odour and itching.
  - Dermatology Life Quality Index (DLQI).
  - Questionnaire for Psychological Distress (CMP).

If the assessment performed reveals emotional distress, these results should be discussed with the patient. If the patient confirms this distress, he or she should be referred to a mental health unit for proper care. If instead the patient does not confirm these results, his or her perception must be respected, and the professional caring for the patient must address the management of the psychosocial considerations present. It is important to bear in mind that if the patient is referred to mental health, it should be made clear that the physician will remain responsible for his or her health and that the referral is merely another link in the treatment and care plan prepared by the physician.

SPECIALISED CARE

- The specialised care setting will probably be where the disease is diagnosed and subsequently monitored throughout the course of the process. Professionals should not focus their efforts exclusively on the physical aspects of the disease. Instead, they must also address the psychological and social aspects associated with the disease.
- The assessment of quality of life and the psychological and social considerations associated with the disease will be measured using the following instruments: VAS (pain, odour and pruritus), DLQI, HADS and CMP.

- If significant emotional distress is detected, care should proceed as proposed in the primary care setting. A first step may be to consult with other professionals, or to hold clinical sessions within departments in order to pool the data obtained and, as applicable, make decisions agreed upon by the team in relation to the physical, psychological and social approach to the patient with HS. This is what is known as a biopsychosocial or holistic approach.

Dermatology departments should promote the establishment of positions for psychologists who may provide the psychosocial care needed in these patients within the department itself. It is important to stress the contribution that these professionals may make to managing of patients with HS.

Some of these contributions may be as follows:

1. Create an emotionally warm, non-critical atmosphere of support and respect that promotes trust and hope.
2. Establish a therapeutic alliance to promote a positive attitude towards treatment and motivation to assume risks that allow the patient to experience new behaviours, feelings and thought processes.
3. Design interventions to relieve suffering and promote changes consistent with the patient's objectives.
4. Seek to incorporate significant emotional, behavioural and cognitive learning into the patient's life.
5. Neutralise irrational fears.
6. Come up with strategies to change maladaptive behavioural patterns, irrational beliefs, dysphoric emotions and self-defeating ways of relating to others.
7. Promote the transfer of new behaviours to the patient's daily life, thus promoting healthy attitudes.

Investigation

Research is a scientific process that validates and improves existing knowledge. It generates new knowledge that influences clinical practice. It is important to conduct research to generate new knowledge in order to ground new care and interventions, as well as their adaptation to social and technological demands, in science.

At present, various research projects in the field of psychodermatology are being conducted. These research projects are intended to generate knowledge related to various skin diseases.

These would include the assessment of psychological impact as well as psychological and educational interventions in patients.

Some of these projects appear in Annex VII.

It would be useful to promote the development of new research projects that generate new knowledge on preparing instruments for measuring the different psychosocial considerations related to HS, as well as to design individual and group interventions and protocols that incorporate patients and family members into the healthcare process.

Dissemination

The main objective of the process of dissemination would be to promote greater knowledge of HS, both in the physical aspects of the disease and in the psychological and social considerations associated with the disease, in society in general. This greater knowledge would help to eradicate taboos, myths and false beliefs related to the disease.

Some interventions intended to inform society about HS are proposed below:

1. Preparation of informational posters and documents to be distributed among professionals in primary care settings as well as specialised care settings (dermatology, surgery and emergency departments). Specific information documents should also be prepared for patients and family members.
2. Training sessions: Patients, families and society.

   Planning of sessions that not only have room for patients and family members of patients with HS, but also are intended for the general population so that more people may attend them and become informed.
3. Higher impact on communication media and social networks (TV, radio, press, internet).

   Increase the visibility of the disease, raise awareness in the population and create networks for connection between professionals and patients.
4. Informational posters in the city to raise awareness in the population.

   Give visibility to the disease in order to improve its diagnosis and raise awareness in society. An example is an experiment performed in Madrid, where information posters on the disease were placed on Metro Line 6.
5. Pioneer project: approaching schools.

   Hold information sessions on HS at schools as a cross-cutting training activity for health as part of school curricula in order to minimise social stigma and promote proper, early detection, especially in adolescents.

Recommendations for managing the psychosocial impact of HS on patients

1. **Train and inform professionals related to HS about the psychological and social impact of the disease** as well as the resources available in the system to face it.

2. **Train and education professionals related to HS In the use of scales** that health help to measure the patient's psychological impairment and quality of life: DLQI, HADS, VAS and CMP-HS.

3. Promote **public opinion training and education efforts** that raise awareness of the disease and serve as a tool against the stigmatisation and lack of understanding that many patients say they feel.

The role of the pharmacist in the comprehensive management of HS

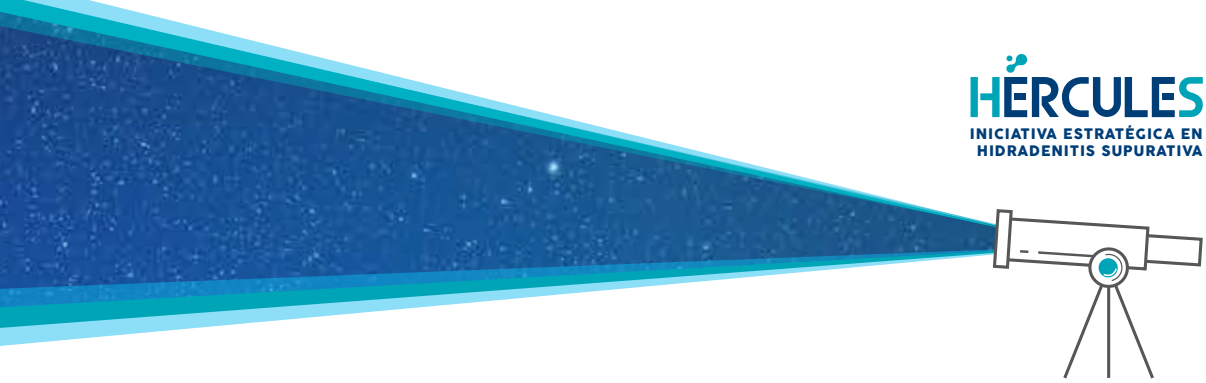
Medicines play an essential, indispensable role in healthcare services. Pharmacists are professionals specifically trained and instructed to manage the supply of drugs to patients and to ensure that medicines are used safely and effectively. Pharmacists also act by ensuring access to quality therapeutic innovation.

Pharmaceutical professionals, in any of the positions that they occupy within the healthcare system, practice as health agents, thus helping to improve access to healthcare, prevent disease and promote health.

The pharmacist should play an overall role that goes beyond the medicine itself and the pharmacotherapeutic process of improving safe drug use, and concerns his or her clinical activity wherein he or she is co-responsible with the rest of the healthcare team for improving clinical, quality of life and economic outcomes. Professionals in the field of pharmacy should:

- Be healthcare agents that are nearby and available for patients
- Ensure the efficacy of medicines
- Manage and report adverse effects, in addition to preventing damage caused by medicines
- Promote responsible use of medicines
- Perform clinical follow-up of patients and their adherence
- Participate in the preparation and use of guidelines and protocols
- Coordinate with other professionals and healthcare levels
- Identify and manage health problems
- Perform health promotion activities

With the increase in chronic diseases in healthcare systems, considerations such as treatment safety, lack of adherence, detection of failures in pharmacotherapy, polymedication, etc., are becoming even more important. Pharmacists may aid in these tasks, not only to improve healthcare expenditure, but also to decrease preventable risks due to system inefficiencies.



As seen, HS is an underdiagnosed chronic disease that affects an essentially young population and may end up seriously affecting the lives of patients who suffer from it. Therefore, pharmacists should get actively involved in managing these patients, since good pharmacy practice may considerably improve the quality of life of the patient with HS.

The HS patient is a chronic patient who, as such, requires comprehensive follow-up in terms of both healthcare and pharmacy care.

The pharmacist should review the suitability and necessity of the prescribed treatment as well as the effectiveness and safety thereof. This is especially significant in the case of HS patients, since an essential part of their therapy is based on prolonged use of antibiotics. In these cases, the pharmacist adds value, in terms of both prescription suitability and treatment adherence by the patient, not only to ensure treatment efficacy but also to act to prevent potential bacterial resistance and predict how this prolonged use of antibiotics may affect other processes and the complications to which it could lead.

For the HS patient, the pharmacist will also act on medication reconciliation. This is particularly significant in the case of HS patients who undergo treatment with biologic therapy, as this requires specific monitoring and suitable administration.

It is important to point out that electronic prescription systems should include the treatment and prescription algorithm for HS patients, as well as the specific requirements associated with certain medications.

Training activities in HS, together with the conduct of studies that improve knowledge of HS, should be promoted among pharmacists.

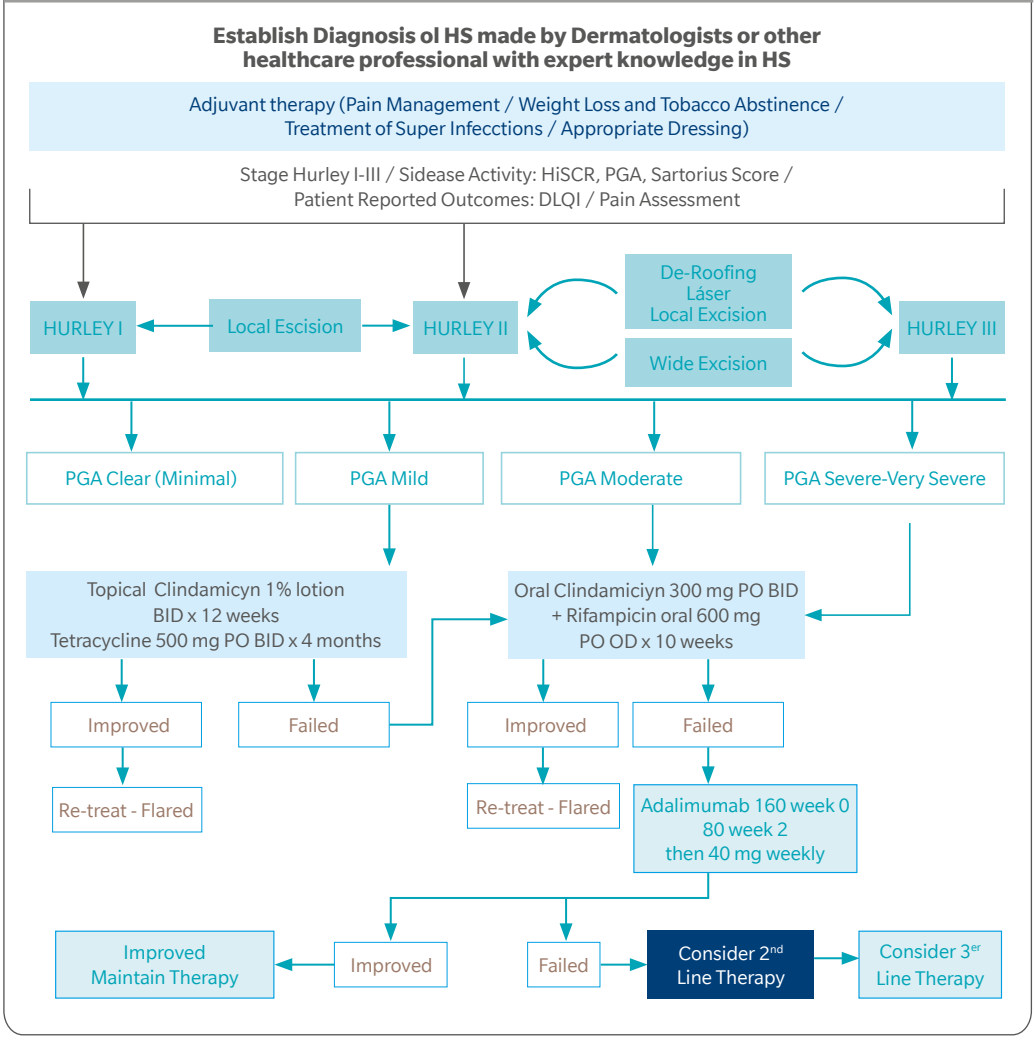
The collaboration between the different pharmaceutical scientific associations already under way may serve as a basis for implementing initiatives and campaigns that help to raise awareness and knowledge of HS in the general population. This would promote early detection of HS in the population and in addition would help to decrease the trivialisation of symptoms, stigma, isolation and lack of understanding suffered by these patients due to the lack of knowledge of their disease.

Algorithm for treatment for the patient with HS

In 2016, the European Guideline for the treatment of HS was published[119]. This included the therapeutic algorithm to be followed with each patient, based on the staging of the seriousness of his or her disease according to the Hurley scale. The algorithm cited appears below.

Figure 24.

Therapeutic algorithm for HS according to the European Guideline for treatment



Recommendations for optimising the role of the pharmacist in the management of the patient with HS

1. **Promote coordination with other healthcare professionals** to achieve a true comprehensive standard of care.

2. Promote **professional training efforts with the collaboration of all Pharmacy SAs.**

3. Promote measures that foster **treatment adherence** by patients.

4. **Add the treatment algorithm for HS to the assisted prescription systems** of the different Spanish Autonomous Communities.

Patient management: patient empowerment and the expert patient

Management of chronic diseases represents one of the most significant challenges for the sustainability of the healthcare system. The care of the chronic patient accounts for close to 80% of healthcare expenditure in Spain.

The Spanish National Health system must make changes that improve efficiency in the management of chronic patients to render this care at once optimal and efficient.

The changes that may be faced are based on the adoption of new models of care for patients with chronic diseases. Disease prevention, health promotion, participation of the patient in the maintenance of his or her own health and in suitable use of resources, self-care, disease management, and case management are common factors in all of them.

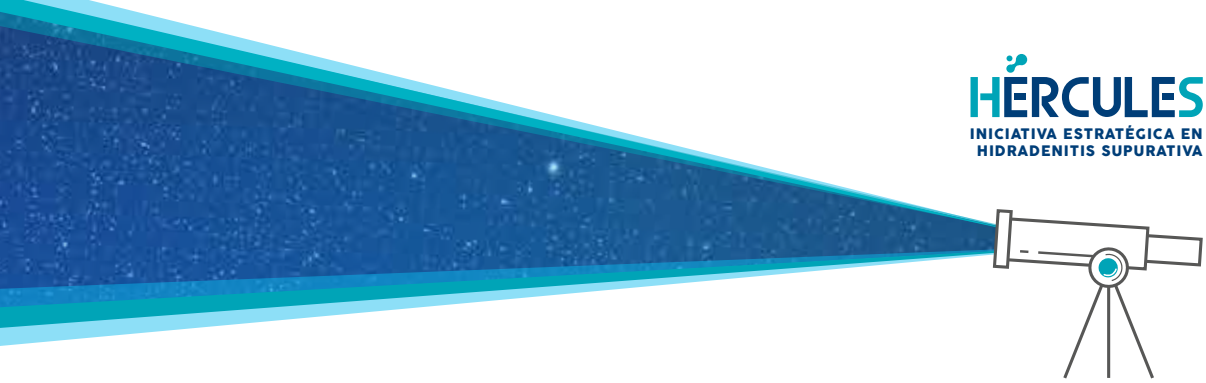
Orientation towards a more efficient model that takes patient participation into account requires healthcare system managers to consider that historically the patient was relegated to a more passive place in which healthcare professionals exclusively made decisions and took responsibility for the outcomes of these decisions.

In the new models, tools should be developed that allow progress to be made towards a relationship of shared decision-making; however, to do this, the healthcare system must improve education for users and encourage training in health and in suitable use of resources so as to improve population health literacy levels. Thus empowered patients may be capable of taking the reins of their own health and, more importantly, actively engaging in shared decision-making on diagnostic and therapeutic procedures.

Empowerment of the patient with HS

Patient empowerment involves a change in the culture of healthcare organisations that involves an improvement in physician–patient communication leading to a more horizontal, less hierarchical and more personalised relationship.

Citizens also have new responsibilities. If the citizen is to assume an active role in the management of his or her own health, then the patient is to face new obligations and changes in his or her action in the system:



- Abandonment of the concept of the passive citizen/patient, and assumption of values of participation and co-responsibility.
- Enhancement of the self-care and autonomy of the patient .
- Co-responsibility of the patient for his or her own health and proper use of healthcare services, for which it is necessary to increase health literacy levels.

En este contexto, nace un nuevo rol del paciente: El paciente activo y el paciente experto.

The Figure of the active patient

An **active patient** is a patient who is competent at managing his or her health problems and self-care and who possesses greater knowledge of his or her disease and, as a result, a better education. This means that the patient is more autonomous in decision-making, has more motivation and is more capable of helping other patients.

An active, or activated, patient is a patient who is able to:

- Know and manage the symptoms of and problems caused by his or her disease
- Participate in activities that maintain and improve his or her health
- Participate in treatment and diagnosis options
- Collaborate with healthcare professionals on suitable use of resources
- Know and select the social and healthcare resources that the system offers to him or her
- Navigate the health system and select quality information that may benefit him or her

How to activate patients

Bearing in mind all of the above, it could be agreed that in order to activate patients, it is necessary to take actions of three types: actions that should be taken by the patients themselves, actions that should be led by patient associations and actions that should be led by healthcare institutions and their professionals.

1. **Actions to be taken by patients:** For a patient to participate in health-related decision-making, what is most important is that he or she wants to participate, and for the patient to want to participate, he or she must be motivated. Communication, information and training in health performed by healthcare professionals and by other patients are essential for the patient to participate.

   The patient may participate individually, by taking co-responsibility for maintaining and improving his or her health, or in a group, from patient associations.

   The patient requires specific training at all times in the course of his or her disease and training to overcome more significant challenges. He or she should be motivated to make lifestyle changes, and it should also be ensured that he or she transfers the lessons learned to daily life.

2. **Actions to be taken by patient associations:** The role of patient associations takes on essential importance in new chronic patient management strategies.

   Patient organisations can and should play an essential role in information on the disease by preparing and disseminating leaflets, videos and articles on the disease and the resources available in the healthcare system to care for it, as well as by endorsing training programmes run by other institutions and healthcare professionals intended for patients with HS.

   In Spain, HS patients belong to the Spanish Hidradenitis Suppurativa Patient Association (ASENDHI) (www.asendhi.org). This is currently the only HS patient association in the Spanish-speaking setting.

   Its objectives are to:

   - Participate in and promote efforts intended to improve people's quality of life and well-being.
   - Promote the training and specialisation of health professionals and other relevant sectors.
   - Promote research by collaborating with centres and researchers, promoting the studies needed and acting as a research centre.
   - Promote awareness-raising in society of the disease by organising informative events as well as collaborating on and preparing publications of interest

     In its work of helping patients with HS, ASENDHI is committed to:
   - The representation and defence of the rights of patients affected by HS.

- The push for quality in the healthcare received by patients with HS by collaborating with healthcare professionals on their work.
- The channelling of information to patients with HS with respect to education and training on the disease, support, assistance, etc.
- Awareness-raising in healthcare and society.
- Collaboration with different administrations, scientific associations, patient organisations, etc.
- The push for the empowerment and activation of patients with HS by:
  - Promoting knowledge of and scientific advances in the disease.
  - Helping patients manage and cope with their disease.
  - Promoting healthy lifestyles.
  - Helping to improve symptom management, communication with health professionals and therapeutic adherence.

For their part, patient associations should adopt a leadership role in implementing awareness-raising efforts, which help to inform the communication media, as well as healthcare professionals themselves, of the disease and its prevention and care.

3. Actions to be taken by healthcare professionals:

Healthcare education is the responsibility of all health professionals. In the best system for training a patient, the same healthcare professional who cares for the patient provides the patient with the training needed. Properly educating patients facilitates proper physician–patient communication as well as decision-making in day-to-day clinical practice.

The nursing staff is most indicated for training in self-care and health resources to improve quality of life, prevent disease and promote health. These professionals know the patient best, and are better able to detect their training needs and capacity for absorbing training, and to assess the transfer of the lessons learned.

Given that these overburdened professionals may not have the time required for this, in some cases, at present, it would be possible to recommend or prescribe workshops, online courses and programmes for patient support such as AbbVie Care, which has a specific programme for patients with HS and websites with rigorous, safe information.

Training/educational sessions for patients may be held individually or in a group and planned.

Individual training may be done in person or using training programmes by telephone or through new technologies by prescribing websites, videos and workshops, with training "pills", with assessment of knowledge, etc. illustrating the concept, prevention, treatment and care of HS.

Group training will be done using training between equals, through the training of expert–tutor patients, who may in turn train other patients with HS, in a domino effect.

All these interventions (from the patient/association or professionals) are intended to increase the activation and modification of the behaviour of patients to promote their com-

mitment, self-care and collaboration with the healthcare system. The Patient Activation Measure (PAM) (Annex VIII) should be used to analyse the course of these interventions. It is currently the only one designed and validated to measure the degree of activation of patients with their own health. This questionnaire was developed by Hibbard et al.90 through a Likert scale. It allows information on patients' knowledge, abilities, beliefs concerning the management of their own care and degree of collaboration with healthcare professionals to be obtained, and maintenance of healthy behaviours with preventive intent to be achieved.

The Figure of the expert patient

The expert patient is a patient who not only is activated but also has the ability to share his or her experience with other patients and to help to train other patients with the same disease, hand in hand with a healthcare professional.

In the 1980s, Kate Lorig, the Director of the Stanford Patient Education Research Centre at Stanford University, implemented education between patients in some chronic diseases. Dr Lorig conducted several studies to validate the efficacy of the courses given, and found that the benefits of education in self-care between patients included: an increase in self-esteem and confidence, incorporation of the management of healthy living habits, a decrease in the number of visits to the family physician and emergency medicine, and better treatment compliance.

The following actions are recommended for implementing the Figure of the expert patient in HS:

1. **Design a training programme for expert patients in HS** jointly between expert professionals and professionals knowledgeable about the expert patient training system and ASENDHI.

   This training should consist of two parts: training on the disease and training to acquire abilities allowing the patient to modify and manage healthy social and living habits adapted to his or her condition.
2. **Prepare materials for online training** with a system similar to that of training "pills" used, for example, at the Galician Health School for Citizens (http://escolasaude.sergas.es/Contidos/Cursos-online) in the HS patient association.

   This course may be used for both in-person and online training on the disease and may form part of the training for expert patients. It may also be posted to the association's website as well as shared and disseminated through the health schools of the different Spanish Autonomous Communities. This achieves the dual objective of educating and raising awareness in society on the disease, and giving it visibility.
3. **Select training professionals and ten patients** to train them as expert–tutor patients. These patients and professionals will constitute a group of trainers to train other patients.
4. Implement the hidradenitis suppurativa expert patient course through the patient association and post the online course to the website. Carry out at least one edition with at least

20 patients trained in the first year, and plan successive editions based on the needs and capacities of the association and professionals.

The recruitment of patients to be trained may be done by healthcare professionals, who detect training needs and propose and/or request the planning of the activity; by patient associations, which detect training needs and perform the activity in their organisations; and by health schools, which would provide the structure and materials needed to perform the activity.

5. **Design the system of assessment of self-efficacy of training.** To do this, it is recommended that the Patient Activation Measure (PAM) system for systematically measuring patient progress[120] and assessing the results of the programmes implemented be adapted and used.

Recommendations to be implemented to achieve the empowerment of the HS patient

1. Develop and disseminate **information material for patients** on HS and healthcare resources, patient association contact information, etc.

2. Plan and implement training efforts for patients in person and online to achieve a group of active and/or expert patients who help to spread models of training between equals. To do this, it is recommended that the patient school network as well as ASENDHI be used, and that healthcare institutions promote patient support programmes.

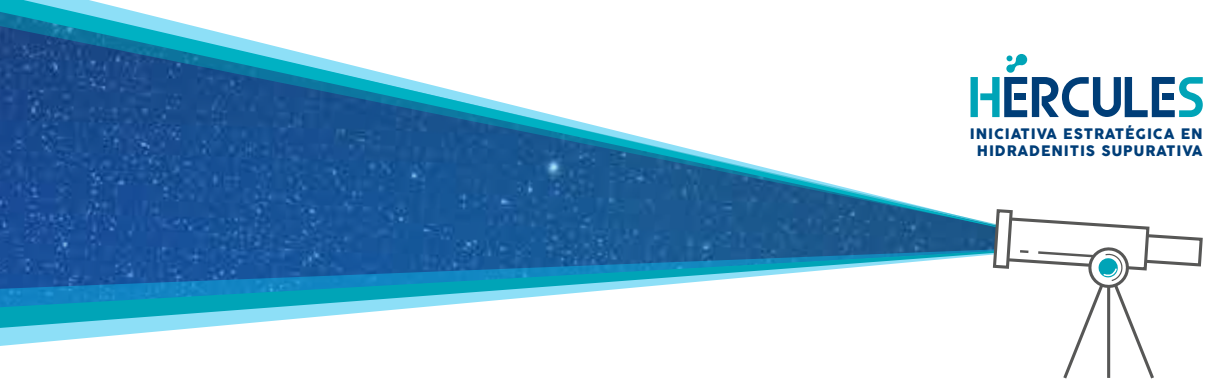
Proposed interventions

DIAGNOSIS

1. **Disseminate the diagnostic algorithm for HS** through the scientific associations for family medicine and primary care, community and primary care nursing, and emergency medicine of the Spanish regional health services using electronic platforms to support healthcare or printing on paper of clear leaflets that present both the algorithm and the images of the lesions most characteristic of HS.
2. Promote and develop **training efforts among primary care and emergency department professionals** for knowledge of HS and criteria for its diagnosis through scientific associations and regional heath services, using both in-person and online training through new technologies and social networks.
3. Establish some **warning mechanism (red flags)** in the information system to help prevent diagnostic confusion of HS with other diseases.

MANAGEMENT OF THE PATIENT IN PC

1. **Disseminate healthcare processes for the management of HS and promote their implementation in the Spanish National Health System wit h the involvement of Scientific Associations** for family medicine dermatology, community nursing aid PC, as well as the involvement of Spanish regional health services.
2. **Publish and disseminiate an information leaflet for patients** accessible at primary care centres and provided to the HS patient by his or her primary care team.
3. **Publish and disseminate the standard of care** presented in Annex I to this document at primary care centres and dermatology departments.
4. **Promote and develop training efforts for PC teams** to improve their knowledge of HS and the criteria for diagnosis and care.
5. **Pilot mechanisms for quick referral to dermatology** in cases of diagnostic uncertainty as well as painful and recurring outbreaks.



MANAGEMENT OF HS IN PAEDIATRICS AND ADOLESCENTS

1. **Promote and develop training efforts for paediatricians** to improve their knowledge of HS and the criteria for diagnosis and care.
2. **Disseminate the diagnostic algorithm** through paediatric scientific associations.
3. **Promote relationships between paediatrics, dermatology and all other specialities to facilitate quick, suitable referral of the child suffering from HS** such that the sequelae left by the disease are minimal.
4. Promote the **HS case registry in childhood and adolescents.**
5. **Promote paediatric HS studies** that provide information on its incidence and prevalence, associated comorbidities, etc.
6. Pubish and disseminate **information leaflets for parents and families** of paediatric patients.

MANAGEMENT OF THE PATIENT IN DERMATOLOGY DEPARTMENTS

1. **Disseminate HS care protocols in dermatology departments** through the AEDV.
2. **Generate awareness of the standard of care** for HS lesions.
3. Promote the existence of at least **one nursing professional in dermatology departments** who assumes the work of healthcare coordination for serious patients, therapeutic patient education and other tasks described in this document.
4. **Extend the use of ultrasound in dermatology departments** to determine the extent course and response of HS lesions in detail.
5. **Promote healthcare coordination between specialists** (dermatologists, gastroenterologists, rheumatologists, family physicians, etc.) through clinical sessions direct communication, etc.
6. **Generalise the implementation of a nursing visit** for the care of HS patients with staff trained in the care of this disease.
7. **Enhance, recognise and disseminate the presence of functional reference units so that they act as consultants** in the management of complex cases of HS for other dermatology departments in the Spanish National Health System.

8. Promote the implementation of **patient registries** that facilitate follow-up and clinical research.
9. Establish **quick referral pathways** from PC, paediatrics, emergency medicine, surgery and dermatology **to ensure healthcare continuity**.
10. Have the SAs involved **prepare a Clinical Guideline** that compiles the consensuses reached in this document.

CARE OF HS IN EMERGENCY DEPARTMENTS

1. **Disseminate the diagnostic algorithm for HS** such that all in-hospital and outof-hospital emergency services have access to it.
2. Examine the implementation of **emergency reference or quick consultation offices** so that a patient who has visited an emergency department due to an outbreak or painful episode is seen by the dermatologist within a few days for diagnostic confirmation, treatment or follow-up of his or her disease.

SURGERY

1. Ensure the continuity of the healthcare process through suitable postoperative care and coordination with the healthcare team responsible for the follow-up of the patient.
2. Ensure coordination within the patient's healthcare team in decision making to minimise the irreversible impact of the lesions.
3. Promote training efforts on HS for surgery professionals.

ASSOCIATED DISEASES: IBD

1. Distribute an **intervention protocol for early detection of HS in IBD departments that recommends investigating the presence of HS in patients with Crohn's disease, obesity or a smoking habit** by applying the diagnostic algorithm for HS and caring for recurring skin lesions in commonly affected areas.
2. **Disseminate a protocol for diagnosis of IBD in patients with HS** through referral to a gastroenterologist, if at least one of the major criteria is met, or at least two of the minor criteria are met, for suspected IBD.
3. **Promote coordination between gastroenterologists and dermatologists** in the follow -up of the disease.
4. **Promote studies** that analyse the relationship between HS and IBD.

ASSOCIATED DISEASES: MENTAL HEALTH

1. **Train and inform professionals related to HS about the psychological and social impact of the disease** as well as the resources available in the system to face it.
2. **Train and education professionals related to HS in the use of scales** that health helto measure the patient's psychological impairment and quality of life: DLQI, HAOS, VAS and CMP-HS.
3. Promote **public opinion training and education efforts** that raise awareness of the disease and serve as a tool against the stigmatisation and lack of understanding that many patients say they feel.

ROLE OF THE PHARMACIST

1. **Promote coordination with other healthcare professionals** to achieve a true comprehensive standard of care.
2. Promote **professional training efforts with the collaboration of all Pharmacy SAs**.
3. Promote measures that foster **treatment adherence** by patients.
4. **Add the treatment algorithm for HS to the assisted prescription systems** of the different Spanish Autonomous Communities.

EMPOWERMENT OF THE PATIENT

1. Develop and disseminate **information material for patients** on HS and healthcare resources patient association contact information, etc.
2. Plan and implement training efforts for patients in person and online to achieve a group of active and/or expert patients who help to spread models of training betwe-n equals. To do this, it is recommended that the patient school network as well as ASENDHI be used, and that healthcare institutions promote patient support or programmes.

A number of priority interventions were selected from all of them with a view to the practicality and feasibility of their application, and also as a result of the debate and consensus.

From the implementation of these proposals it is feasible to obtain results with a major impact on improvement of the diagnosis, management, treatment and quality of life of patients with HS.

THE PRIORITY ACTION INTERVENTIONS ARE AS FOLLOWS

1. Implementation of **training efforts for professionals** with the help of the scientific associations involved. Training efforts may be carried out in person or, for the most part, online. The specialities in which training activity should be intensified are as follows: Family and community medicine, community and PC nursing, paediatrics, dermatology, emergency medicine, general surgery, cosmetic surgery, gastroenterology, and rheumatology.
2. **Dissemination of the diagnostic algorithm** through scientific associations, especially for family and community medicine, community and primary care nursing, emergency medicine, dermatology, and paediatrics, and through the electronic platforms of the different Spanish regional health services.
3. Publish and distribute **information materials intended for patients** at primary care centres and dermatology services in particular.
4. **Disseminate the healthcare protocols and processes** that appear in this document with the help of the Scientific Associations involved and with the regional health services of the different Spanish Autonomous Communities.
5. **Promote mechanisms for quick referral to dermatology** from primary care, paediatrics and emergency medicine in cases of reasonable diagnostic uncertainty, cases in paediatric and adolescent patients, complex cases, and cases that do not respond to treatment.
6. Promote the establishment of **HS patient registries** in the different Spanish Autonomous Communities as a precursor to a Spanish national patient registry.
7. **Promote the Figure of functional reference units** that act as consultants for other dermatology departments and disseminate their existence through the AEDV.
8. **Promote mechanisms for communication between professionals** to ensure healthcare and care continuity for HS patients. In this regard, the need to ensure coordination and healthcare **continuity in patients when they must undergo a surgical procedure should be noted.**
9. Implement **a protocol to detect HS in patients with IBD and a protocol to detect IBD in patients with HS.**
10. Perform **training efforts for professionals** related to HS on the scales to measure quality of life and psychological and emotional impact on the patient, as well as the measures to be taken in patients with marked impairment.
11. Implement a **public opinion education campaign** to educate the public about the disease.
12. **Implement the appropriate mechanisms for HS to be recognised as a cause of handicap or disability**.

13. **Add the treatment algorithm for HS to the assisted prescription systems** of the different Spanish regional health systems.
14. Design and implement a **training course for expert patients** in collaboration with ASENDHI and the patient school network.

As a conclusion to all the work done by the expert panel, an attempt has been made to compile the complete healthcare process that an HS patient should follow in a single graphic. It presents the journey that the patient should make through the system to ensure suitable diagnosis and optimal management of his or her disease.

Compiling the healthcare pathway of the HS patient in a single process encompasses in itself the desire that may be deduced from each chapter of this document: the achievement of a true healthcare continuum in which, under the leadership of the general practitioner in mild cases and the dermatologist in moderate and severe cases, the HS patient has within his or her reach all system resources available to ensure a comprehensive, efficient, effective and high-quality approach to his or her disease.

Complete healthcare process for the management of HS

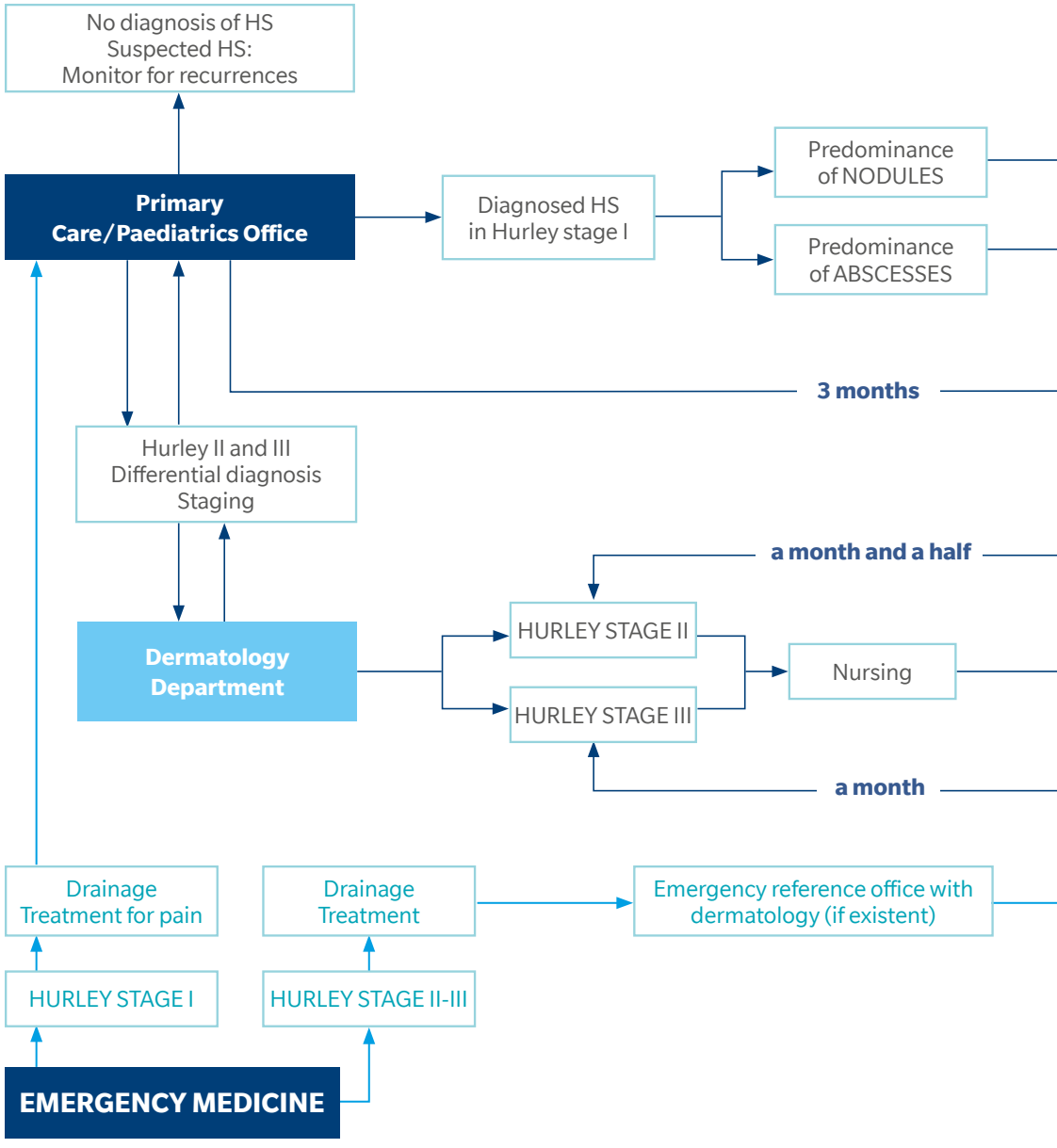
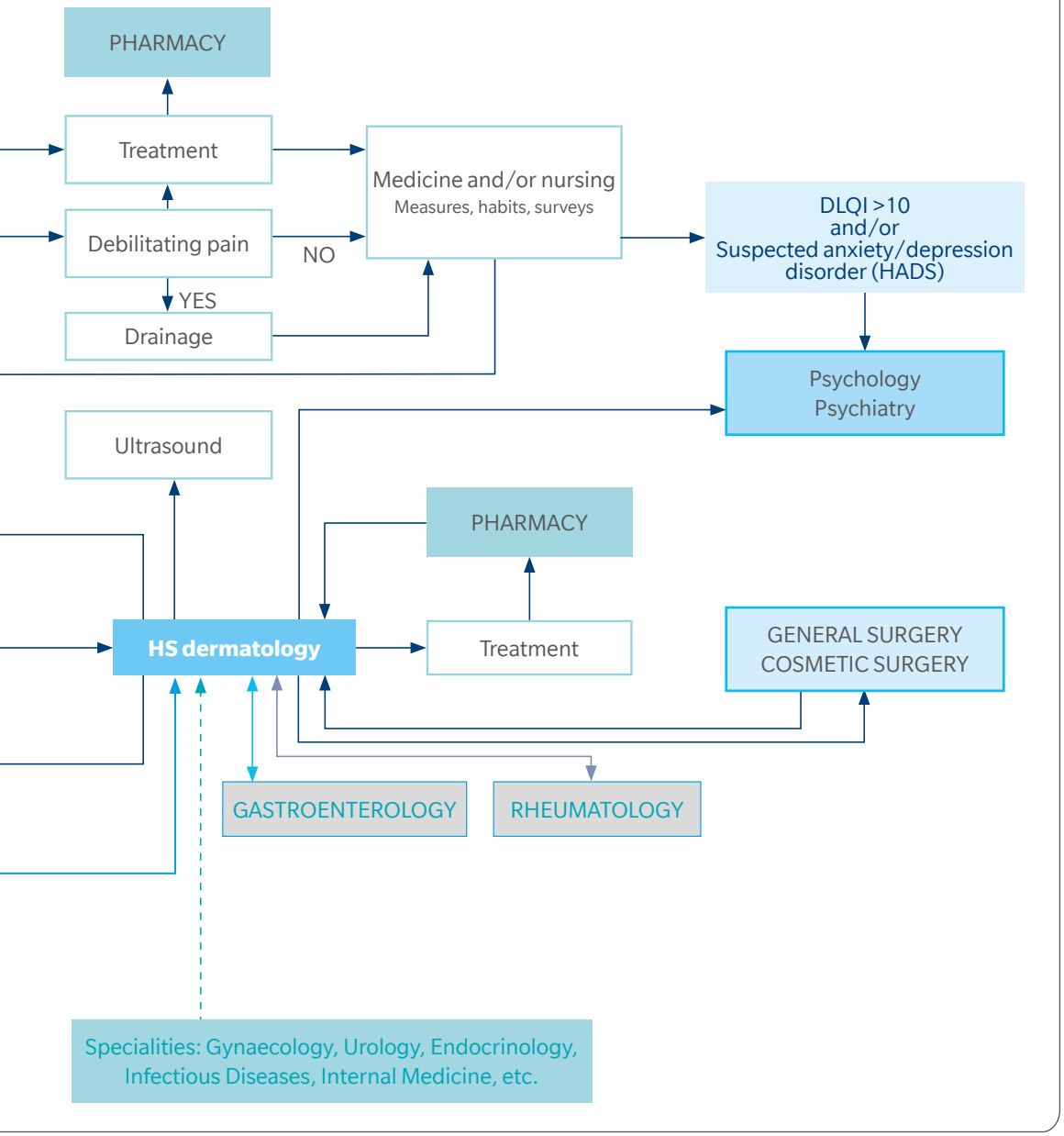


Figure 25.


PHARMACY
Treatment
Debilitating pain
YES
Drainage
NO
Medicine and/or nursing
Measures, habits, surveys
DLQI >10
and/or
Suspected anxiety/depression
disorder (HADS)
Psychology
Psychiatry
Ultrasound
PHARMACY
HS dermatology
Treatment
GENERAL SURGERY
COSMETIC SURGERY
GASTROENTEROLOGY
RHEUMATOLOGY
Specialities: Gynaecology, Urology, Endocrinology,
Infectious Diseases, Internal Medicine, etc.

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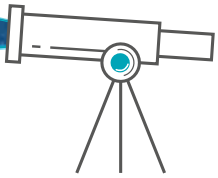

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Annex

Annex I: Standard of care based on the lesion to be treated

Nodules (inflammatory or non-inflammatory)

Treatment scheduled by the physician: topical treatment (clindamycin) and injection (corticosteroids between lesions: mepivacaine 2% + Trigon [triamcinolone acetonide] or betamethasone).

Abscesses

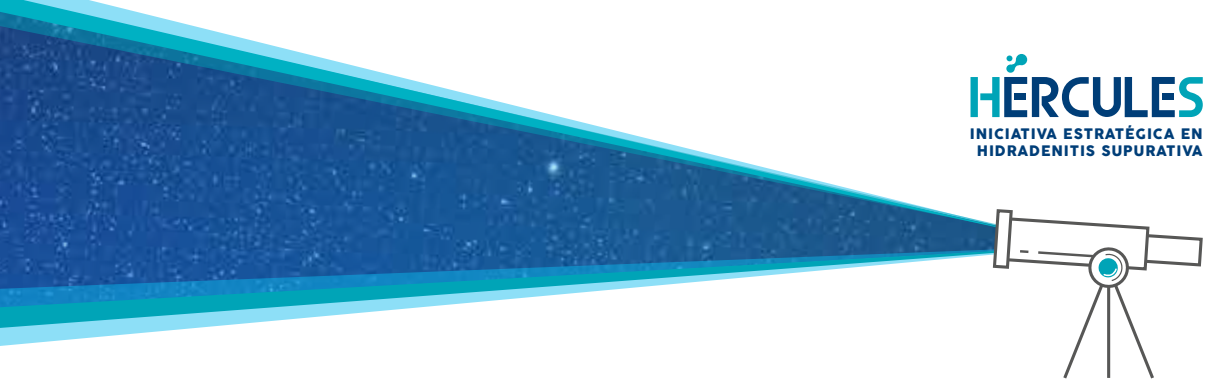
When these require drainage:

1. Administer a local anaesthetic.
2. Make an incision with a scalpel blade.
3. Open the lesion slightly with dissecting forceps, Adson forceps or mosquito forceps, so that the contents come out (these do not tend to be purulent).
4. Leave a piece of cotton gauze inserted.
5. Optionally, apply topical antibiotic (fusidic acid). This is especially indicated if the patient will not take oral antibiotic.
6. Place a bandage (this should be very absorbent, keep the area dry, conform to the anatomical region, have a good adhesive, be non-irritant and prevent odour).

   Currently, no specific bandages for HS are available. The bandages used should be highly absorbent and highly flexible.
7. A charcoal disc may be added (this absorbs odour).
8. Prescribe oral antibiotic.

Fistulas

1. Irrigate the inside of the fistula with normal saline to clean it, should any purulent matter be present.
2. Clean the outer area with antiseptic soap (chlorhexidine, iodine) well diluted with normal saline.
3. Apply a bandage (this should be absorbent and flexible).
4. Secure the dressing with the most appropriate material for each location: tubular mesh or paper surgical tape.



Annex II: Psychoeducation in hidradenitis suppurativa

Proposed contents for the information leaflet intended for patients

Hidradenitis suppurativa is a chronic skin disease. At present there is no cure. Even so, it is possible to manage outbreaks and their symptoms.

The skin areas affected by hidradenitis suppurativa tend to be the armpits, groin, buttocks, area around the anus and folds below the breasts. This means that proper hygiene and hydration are important:

- Drink 1.5-2 litres of water or fluids (tea, juice, broth, etc.) per day.
- In the bath or shower, avoid using aggressive soaps as well as sponges and other utensils that may irritate or damage the skin.
- Use soaps and/or creams recommended by your specialist.
- Do not apply cologne or perfume directly to the affected skin area, as this may irritate it more.
- When you are getting dressed, it is best to use fabrics such as cotton or linen, rather than wool or artificial fibres, which may increase skin irritation and itching. Avoid using tight clothing, especially in the areas involved.
- Avoid shaving the affected areas. Talk to your specialist about the most suitable methods of hair removal.

Other important matters to bear in mind in people with hidradenitis suppurativa are as follows:

- Try to follow a diet that is suitable for you personally so as to prevent the worsening of concomitant diseases (diabetes, cholesterol, etc.) and overweight (avoid friction).
- Reduce alcohol intake and avoid smoking. Both contribute to worsening, especially smoking. If you need help to stop smoking, talk to your specialist.
- To the extent possible, exercise 2 or 3 times per week and avoid sedentary living.
- Get a good night's sleep.

IF YOU HAVE ANY QUESTIONS, ALWAYS TALK TO YOUR GENERAL PRACTITIONER OR DERMATOLOGIST

Annex III: DLQI:
Dermatology Life Quality Index (DLQI)

DERMATOLOGY LIFE QUALITY INDEX* (DLQI)

Patient: ..... Date: .....

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

Please check you have answered EVERY question. Thank you.

1.	Over the last week, how **itchy, sore, painful** or **stinging** has your 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 ☐
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 ☐
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 ☐
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 ☐
7.	Over the last week, has your skin prevented you from **working** or **studying**?	Very much ☐ A lot ☐ A little ☐ Not at all ☐		Not ☐

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 ☐
9.	Over the last week, how much has your skin caused any **sexual difficulties**?	Very much ☐ A lot ☐ A little ☐ Not at all ☐	Not ☐
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 ☐

** A.Y. Finlay and G.K. Khan, Dermatology Life Quality Index (DLQI) — A simple practical measure for routine clinical use. Clinical and Experimental Derm. 1994;19(3):210-16.*

Annex IV: Visual analogue scale (VAS) for odour, pain and itching

VAS for ODOUR

PATIENT:..... *DATE:* .....

Draw a vertical line at the point that best describes your perception of body odour caused by your lesions. The left end represents no odour and the right end represents the most odour imaginable.

VAS for PAIN

PATIENT: ..... *DATE:* .....

Draw a vertical line at the point that best describes your perception of pain caused by your HS. The left end represents no pain and the right end represents the most pain imaginable.

VAS for ITCHING

PATIENT: ..... *DATE:* .....

Draw a vertical line at the point that best describes your perception of itching caused by your HS. The left end represents no itching and the right end represents the most itching imaginable

Annex V: Hospital Anxiety and Depression Scale (HADS)

Original version by Zigmond and Snaith, 1983

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he or she will be able to help you more. This questionnaire is designed to help your doctor know how you feel. Read each item and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or 'wound up' (A)

- Most of the time
- A lot of the time
- Time to time, occasionally
- Not at all

2. I still enjoy the things I used to enjoy (D)

- Definitely as much
- Not quite so much
- Only a little
- Not at all

3. I get a sort of frightened feeling like something awful is about to happen (A)

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

4. I can laugh and see the funny side of things (D)

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

5. Worrying thoughts go through my mind (A)

- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

6. I feel cheerful (D)

- Not at all
- Not often
- Sometimes
- Most of the time

7. I can sit at ease and feel relaxed (A)

- Definitely
- Usually
- Not often
- Not at all

8. I feel as if I am slowed down (D)

- Nearly all of the time
- Very often
- Sometimes
- Not at all

9. I get a sort of frightened feeling like 'butterflies in the stomach' (A)

- Not at all
- Occasionally
- Quite often
- Very often

10. I have lost interest in my appearance (D)

- Definitely
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

11. I feel restless as if I have to be on the move (A)

- Very much indeed
- Quite a lot
- Not very much
- Not at all

12. I look forward with enjoyment to things (D)

- A much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

D. I get sudden feelings of panic (A)

- Very often indeed
- Quite often
- Not very often
- Not at all

13. I can enjoy a good book or radio or TV programme (D)

- Often
- Sometimes
- Not often
- Very seldom

Questions relating to anxiety are indicated by an 'A' while those relating to depression are shown by a 'D'. Scores of 0-7 in respective subscales are considered normal, with 8-10 borderline and 11 or over indicating clinical 'caseness'.

Annex VI: Questionnaire for Psychological Distress in Hidradenitis Suppurativa (QPD-HS)

This questionnaire is based on the principles of emotional/behavioural therapy and cognitive restructuring. It was designed to detect emotional distress and concerns about HS. It is a brief instrument and may be useful in clinical practice.

The patient is asked the following questions in the order indicated. Based on his or her answers, referral to mental health may be proposed to the patient

1. **How are you currently feeling with respect to your disease (HS)?**

   This question seeks to determine the patient's basic emotions, such as: sadness, happiness, anger, etc. It allows the patient's type of emotional coping with his or her disease to be determined.

   The following should raise a red flag: feelings of sadness, irritability, negative coping, suicidal ideation, etc.

2. **What would you like to improve in relation to your disease (HS)?**

   This question is intended to determine the patient's expectations with respect to his or her disease. This knowledge will aid in preparing strategies to correct potential dysfunctional or maladaptive expectations.

   The following should raise a red flag: lack of expectations, negativity, dysfunctional coping, etc.

3. **How may I help you in relation to your disease (HS)?**

   This question is intended to determine the patient's thoughts and beliefs in relation to his or her disease

   The following should raise a red flag: request for psychiatric, psychological, social, etc. care.

If significant emotional distress is detected from the answers obtained from the patient, potential referral to mental health should be proposed, or other professionals who may provide regimens for management and monitoring of the psychosocial impact present should be consulted.

Questionnaire for Psychological Distress in Hidradenitis Suppurativa (QPD-HS)

1. **How are you currently feeling with respect to your disease (HS)?**
   - NOTES:
   - RED FLAGS: YES NO NOT SURE
2. **What would you like to improve in relation to your disease (HS)?**
   - NOTES:
   - RED FLAGS: YES NO NOT SURE
3. **How may I help you in relation to your disease (HS)?**
   - NOTES:
   - RED FLAGS YES NO NOT SURE

CMP-HS: Correction keys

- **Has no red flags:** Usual follow-up
- **Has 1 or 2 red flags but does not ask for help:** Short-term follow-up and another QPD-HS assessment in 3 months are recommended.
- **Has 3 red flags and/or asks for help:** Refer to Mental Health with the prior agreement of the patient.

Annex VII: Research projects in the field of psychodermatology

Project GEDEPSI-AEDV-2-HSQoL-2015

Project title: Development and Validation of an Instrument to Assess Quality of Life in Patients with HS.

Favourable opinion: Aragon Clinical Research Ethics Committee (ACREC/CEICA).

Principal investigator: Servando E. Marrón Moya, Spanish national coordinator, GEDEPSI, Hospital de Alcañiz.

Design: A prospective, multicentre study conducted within the Spanish Psychiatric Dermatology Research Group (GEDEPSI) of the Spanish Academy of Dermatology and Venereology (AEDV).

Project IIBSP-HID-2016-19

Project title: Group Psychotherapy for Patients With Hidradenitis Suppurativa: Effects in Quality of Life.

Favourable opinion: Clinical Research Ethics Committee (CREC), Healthcare Management Foundation (FGS), Santa Creu i Sant Pau Hospital, Barcelona.

Principal investigator: Esther Margarit de Miguel, research psychologist, Santa Creu i Sant Pau Hospital.

Design: Randomised longitudinal experimental intergroup control group study. Sampling will be probabilistic with random assignment to the intervention group. The control group will be the waiting group.

Project IIBSP-PSI-2016-71

Project title: A Comparative Retrospective Study Between Patients With Hidradenitis vs Patients With Psoriasis: Psychological Impact.

Favourable opinion: Clinical Research Ethics Committee (CREC), Healthcare Management Foundation (FGS), Santa Creu i Sant Pau Hospital, Barcelona.

Principal investigator: Esther Margarit de Miguel, research psychologist, Santa Creu i Sant Pau Hospital.

Design: A comparative retrospective cross-sectional study between two groups.

Notes

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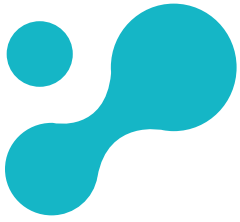

Declarado de interés docente o de utilidad por la

AEG

Asociación Española de Gastroenterología

Declarado de interés docente por

GETECCU

Grupo Español de Trabajo en Enfermedad de Crohn y Colitis Ulcerosa

Con el Aval Científico de la

Aval de Calidad y Garantía

Documento considerado de interés científico por SEMES

Actividad validada por

Las opiniones expresadas por los organizadores no reflejan necesariamente la postura de la SEPD

abbvie

ES/HUD/0517/0782 (Mayo 2017)