

UNDERSTANDING THE BURDEN OF HIDRADENITIS SUPPURATIVA (HS) IN MEXICO

KEY FINDINGS FROM “VOICES OF HS IN MEXICO: A QUALITATIVE STUDY ON QUALITY OF LIFE”

ABOUT THE AUTHORS



Fundación IDEA is an independent, non-profit public policy research center based in Mexico, with over 20 years of experience in the design, evaluation, and analysis of public policies across Latin America.

This study was conducted in collaboration with the Mexican Foundation for Dermatology (FMD) and received non-commercial financial support from UCB.

WHY THIS MATTERS

Hidradenitis Suppurativa (HS) is a chronic, inflammatory condition that significantly impacts the quality of life of people living with it. Despite its severity, HS remains underdiagnosed, under-recognized, and often underprioritized, particularly outside specialized care settings.

While global research has increasingly documented the clinical aspects of HS, there is still limited evidence on its lived experience—especially in Latin America. This gap constrains the ability of health systems and decision-makers to fully understand the broader burden of the disease and respond effectively.

Understanding HS from a patient-centered perspective is essential to identifying gaps in care, improving health system responses, and designing more effective interventions.

This study addresses this gap by documenting the experiences of people living with HS, their family members, and healthcare professionals in Mexico, offering a more comprehensive and systemic understanding of the condition.

ABOUT THE STUDY

“Voices of Hidradenitis Suppurativa (HS) in Mexico: A Qualitative Study on Quality of Life” was conducted by Fundación IDEA based on 35 in-depth interviews with people living with HS, family members, and healthcare professionals.

The study builds on international frameworks on health-related quality of life while developing a context-specific methodological approach that integrates physical, emotional, social, and economic dimensions, as well as access to healthcare as a cross-cutting factor.

This methodological design is adaptable and can be replicated in other Latin American contexts facing similar evidence gaps. Detailed methodology, data, and references are available in the full report.

KEY FINDINGS


01

HS HAS A PROFOUND PHYSICAL IMPACT THAT EXTENDS BEYOND SYMPTOMS

HS is experienced as a condition marked by chronic pain, inflammation, and recurrent flare-ups that significantly limit daily functioning. These symptoms affect mobility, energy levels, and the ability to carry out basic activities.

Beyond acute symptoms, people living with HS describe a continuous physical burden shaped by daily care routines, including wound management and symptom control. This often leads to exhaustion and, in some cases, a loss of autonomy when support from others becomes necessary.

Sleep disturbances are also a critical but often overlooked impact. Pain, discomfort, and fear of worsening symptoms disrupt sleep patterns, contributing to cumulative fatigue.



“There are times when even lying down hurts, sitting hurts, everything hurts. There’s no position where I feel okay.”

— Person living with HS

02


THE EMOTIONAL AND PSYCHOLOGICAL BURDEN IS DEEP, PERSISTENT, AND RELATIONAL

HS also affects self-image and identity over time. Many individuals describe a shift in how they perceive their bodies, as well as uncertainty about their future, including person-

al relationships, life plans, and long-term well-being.

Importantly, this emotional burden is not experienced in isolation. Family members also report stress, sadness, and a sense of helplessness when witnessing the impact of the condition, highlighting that HS operates as a shared and relational experience.

At the same time, some individuals develop coping strategies and forms of resilience, including peer support, therapy, and personal reframing of their experience.



“I’ve struggled with anxiety and depression... there were moments when I didn’t see a way forward.”


— Person living with HS

03

HS RESHAPES SOCIAL LIFE AND CAN LEAD TO ISOLATION

HS significantly affects social participation and interpersonal relationships. Pain, visible symptoms, odor, and fear of stigma often lead individuals to withdraw from social settings, cancel plans, or avoid physical proximity to others.

This reduction in social participation is not only due to physical limitations but also to anticipated judgment and the need to explain a poorly understood condition. The impact extends to intimate relationships, where insecurity and discomfort with one’s body can affect emotional and physical closeness.



“You feel like your life depends on the disease... like you’ve been taken hostage by it.”

— Person living with HS


04

HS CREATES A SUSTAINED ECONOMIC BURDEN AND DISRUPTS WORK AND EDUCATION

The financial impact of HS is substantial and ongoing. People living with HS report allocating a significant portion of their income to consultations, treatments, medications, and daily care supplies.

At the same time, the condition affects employment stability and productivity. Recurrent flare-ups, medical appointments, and physical limitations can lead to absenteeism, job changes, or reduced work opportunities. The impact also extends to education, with some individuals reporting interruptions or delays in their academic trajectories due to the severity of symptoms.

These combined effects create a cycle where increased healthcare needs coincide with reduced economic stability.



“I had to give up opportunities —not because I didn’t have the skills, but because physically I couldn’t keep up.”

— Person living with HS

05

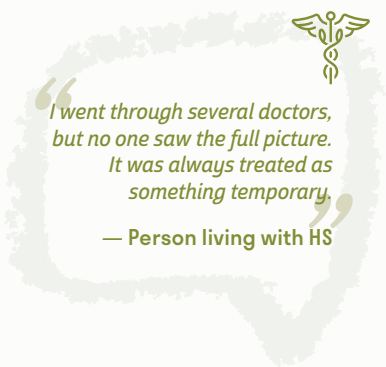
ACCESS TO HEALTHCARE IS A DEFINING FACTOR IN THE OVERALL BURDEN OF HS

Access to timely, accurate, and comprehensive healthcare plays a critical role in shaping the HS experience. A central finding of the study is the significant delay in diagnosis, with an average of nearly 9 years between symptom onset and correct identification of the condition. During this time, individuals often receive multiple misdiagnoses and ineffective treatments.

Beyond diagnosis, people living with HS face fragmented care pathways. The condition often requires coordination across multiple medical specialties, which is not always available or accessible.

Importantly, barriers are present across both public and private healthcare systems. Challenges include limited awareness among healthcare professionals, lack of integrated care models, administrative barriers, and financial constraints.

These gaps contribute to disease progression, increased physical and emotional burden, and reduced quality of life.



WHAT THESE FINDINGS HIGHLIGHT

The findings show that HS is a multidimensional condition with cumulative and interdependent effects across physical, emotional, social, and economic domains.

The study also highlights that the burden of HS extends beyond individuals to their families, reinforcing the need to understand the condition as a systemic and relational experience.

Current approaches to HS are often insufficient to address this complexity. Addressing the condition effectively requires moving beyond isolated clinical management toward more integrated, person-centered models of care.

Access to healthcare emerges as a key factor that can either mitigate or intensify this burden, depending on the availability of timely diagnosis, specialized care, and coordinated treatment approaches.

KEY AREAS FOR STRENGTHENING HS RESPONSE

- ▶ Improve early detection and diagnostic pathways
- ▶ Strengthen training and awareness among healthcare professionals
- ▶ Expand access to coordinated, multidisciplinary care
- ▶ Integrate mental health support into standard care
- ▶ Promote public awareness and reduce stigma around HS

Addressing HS requires moving beyond symptom management toward comprehensive, person-centered approaches that reflect the full burden of the condition and the lived experiences of those affected.



TO ACCESS AND DOWNLOAD THE FULL REPORT
(AVAILABLE IN SPANISH):

[HTTPS://BIT.LY/30FGHHK](https://bit.ly/30FGHHK)

