

Voice of the Hyperhidrosis Patient:

Symptoms, Impacts & Treatments:

Insights from Large, Open, FDA-Attended Meeting

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Disclosures

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Allergan, Investigator, Grants, paid to UTHealth McGovern Medical School, Not relevant to topic
Brickell, Investigator, Grants, paid to UTHealth McGovern Medical School, Not relevant to topic
Dermira, Advisory Board, Honoraria, paid to UTHealth McGovern Medical School, Not relevant to topic
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Evolus, Investigator, Grants, Not relevant to topic
Galderma, Investigator, Grants, Not relevant to topic
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The International Hyperhidrosis Society's Patient-Focused Drug Development Meeting (PFDD), from and around which this data was collected, was funded in part by unrestricted grants from Dermira, RA Fischer, Brickell Biotech, and Hidrex USA.

Background:

Hyperhidrosis (Hh) is characterized by extreme sweating beyond what is necessary/expected for thermoregulation, or as a stress reaction. There are ~**15.3 million** individuals with Hh in the U.S. (**prevalence 4.8%**).¹ Related discomfort, occupational hindrances, and psychosocial impacts are noted in the literature.²⁻⁴ Treatment options exist, but patient satisfaction can be low and access challenging.⁵

To add to the understanding of what would constitute patient-centric approaches, the International Hyperhidrosis Society hosted a Patient-Focused Drug Development (PFDD) meeting on Hh as part of the U.S. Food & Drug Administration's Externally-led PFDD initiative.

Objectives:

To use qualitative methods in the context of an Hh sufferer forum to gather perspectives on disease manifestation, research and treatment. To illuminate condition context and make known sufferers' care priorities.

References:

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3. Kamudoni P, Mueller B, Halford J, Schouvellier A, Stacey B, Salek MS. The impact of hyperhidrosis on patients' daily life and quality of life: a qualitative investigation. Health and Quality of Life Outcomes. 2017 15:121.
4. Bahar R, Zhou P, Liu Y, et al. The prevalence of anxiety and depression in patients with or without hyperhidrosis (HH). J Am Acad Dermatol. 2016;75(6):1126-1133.
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Methods:

This PFDD meeting was held November 13, 2017 as a forum for self-identified Hh patients, caregivers and other stakeholders to share insights into disease symptoms, daily impacts that matter most, current research design and treatment approaches. Qualitative results were generated from transcripts of attendee (**125**) presentations, pre-event poll (**150+ responses**), live webcast (**350 participants**) and post-meeting open comment period (**100+ comments**).

Results:

Insights from individuals on Hh symptoms, impacts, and treatments showed frequent themes including: childhood/adolescent onset and early challenges (in poll, 55% say Hh started at age 10 or younger); indications that Hh has “ruined” life, “controls” life; feelings of self-harm/suicide, anxiety, isolation, depression; limited or “no” treatments for non-axillary Hh; feeling cold and/or painful hands/feet; slips and falls; thoughts of hopelessness with current treatments; frustration at “having tried everything”; desire to get to “root” cause; fear that offspring will “get” Hh; limited access to care; desire for clinicians and regulators to be more informed on Hh.

In poll:

- >70% moderately/extremely dissatisfied with clinical Hh knowledge
- >75% of Hh sufferers reported asking for medical care for Hh more than 3 times
- 95% say their Hh is not resolved

Testimonials from Hh Sufferers on Living with Excessive Sweating:

Social, Emotional & Self-Concept Responses

“Always the outcast”
“Doomed”
“Ashamed to be touched”
“Isolating and embarrassing”

“Always anxious”
“Never able to become who I am”
“Very hopeless”
“I feel gross”

“Never, ever able to get home without being on the verge of tears”
“Constantly wet”
“I don’t want people near me. I don’t want to be touched”

Thoughts on Current Clinical Experiences & Treatments

“Overlooked”
“Poorly managed”
“Temporary”
“People with hyperhidrosis are desperate for treatment. We are desperate to find relief”

“Not enough treatments available”
“Expensive”
“Under-treated”
“I would give up both pinky fingers [for effective treatment]”

“Make-do”
“Painful”
“No insurance coverage”
“When the patient is the expert, rather than the doctor, that’s a difficult situation”

Expressed Desires for Future Hh Care

“Better clinical trials”
“Accessible, affordable [treatments]”

“Educate, educate, educate”
“Better treatment options”

“There’s no hope for me. But, I hope there will be for people in the future”

Conclusions:

Sufferers and caregivers offer valuable perspectives on the broader context of Hh, and their experience with care and research. Insights collected from this meeting may be useful during benefit-risk assessments, regulatory review, fit-for-purpose study design, treatments and patient-driven care.