

# Understanding Patient Experience With Hyperhidrosis: A National Survey of 1,985 Patients

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## ABSTRACT

Hyperhidrosis affects 4.8% of the US population, and despite the well documented negative impact of hyperhidrosis on patients' lives, data are generally lacking on the patient experience with this condition. The International Hyperhidrosis Society (IHHS) conducted a study in 2014, and initial results confirmed the multifaceted impact of hyperhidrosis on quality of life and underscored the need for disease awareness and effective management. To provide further insight into the hyperhidrosis patient experience, additional results focusing on family history, physician interaction, impact on daily activities, and treatment satisfaction are presented here. The online survey included 22 multiple-choice questions (some allowing multiple responses). Respondents were IHHS newsletter registrants in the US self-identified as suffering with excessive sweating (ie, answering 'yes' to Question 1). Of 28,587 survey invitations, a total of 5,042 recipients (17.6%) opened the e-mail, and 2,045 respondents provided an answer to Question 1. Of these, 1,985 (6.9%) self-identified as having excessive sweating and continued the survey. Over 18% of survey respondents reported an immediate family member with excessive sweating. The top three areas impacted by excessive sweating were daily activity, clothing choice, and work/career (average rank scores over 3.0 for each area; range 1-8 with lower scores indicating greater impact). Nearly half (48.9%) of respondents reported waiting 10 or more years prior to seeking medical help, and 85.0% waited at least 3 years. Of the 87.2% of respondents who received treatment for hyperhidrosis, patients were most satisfied with injections and least satisfied with prescription and over-the-counter antiperspirants and liposuction. These survey results add important clinical insight for the underserved hyperhidrosis patient population. The reported delay in seeking proper medical attention highlights the need to increase hyperhidrosis awareness among the public and clinicians, to reduce stigma associated with the condition, and to encourage active treatment strategies.

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## INTRODUCTION

**H**yperhidrosis (HH) is a condition in which sweat production exceeds that which is physiologically necessary to maintain thermal homeostasis.<sup>1</sup> The most recent estimate of HH prevalence in the United States is 4.8%, or approximately 15.3 million people.<sup>2</sup> Numerous clinical trials have demonstrated the negative impact that HH has on a patient's quality of life,<sup>1,3-5</sup> and a recently published study in more than 2000 participants found that the prevalence of anxiety and depression was significantly higher in those with HH than those without HH (21.3% vs 7.5% and 27.2% vs 9.7%, respectively).<sup>6</sup>

Despite the negative impact to patients, the perception that HH is not a "real" medical condition persists, and can leave those with HH suffering in silence.<sup>2</sup> Patients' inability to interpret their symptoms as a medical condition leads to a delay in seeking (or a complete reluctance to seek) treatment, as seen in previous reports.<sup>2,7</sup> Though specific treatment choices may differ depending upon location of excessive sweating and intrinsic patient characteristics, in general, treatments for HH span a broad range of therapeutic approaches.<sup>1</sup> Commonly used therapies include

topical use of antiperspirants (eg, aluminum salts), iontophoresis, botulinum toxin injections, and microwave thermolysis (for axillary HH only).<sup>8</sup> Additionally, systemic anticholinergic drugs have been used with some success, though corresponding adverse events such as dry eyes, dry mouth, and bowel or bladder dysfunction are limiting.<sup>8</sup> If these first-line treatments are ineffective or unavailable, invasive or surgical procedures, such as direct excision of the sweat glands, can be considered in selected cases.<sup>9</sup> The most invasive surgical approach is endoscopic thoracic sympathectomy, which has shown positive results, though the potential for adverse effects, particularly compensatory sweating, remains a concern.<sup>9</sup>

The International Hyperhidrosis Society (IHHS) is currently the only non-profit organization advocating in the interest of patients with HH and supports ongoing research efforts in the therapeutic area.<sup>10</sup> In 2014, a national questionnaire-based survey of IHHS newsletter registrants in the US was undertaken, and the results provided insight into HH multifocal patterns, changes in condition severity over time, and changes across

seasons.<sup>11</sup> Importantly, these findings confirmed the multifaceted impact of HH on quality of life and underscored the need for disease awareness and effective management. In addition, these survey findings indicated that commonly held perceptions of HH regressing over time and/or changing based upon seasons may not be the experience for many HH patients. Clinical insights gained from such data can reinforce best practices (eg, prioritizing treatment regimens that are safe and effective across a patient's life span and consistent throughout the year).

Even with the well documented negative impact of HH on patients' lives, data are generally lacking on the patient experience with this condition. To provide further insight into the HH patient experience, additional findings collected during the 2016 IHHS survey focusing on family history, physician interaction, impact to daily activities, and treatment satisfaction are presented here.

## METHODS

The methodology has been previously published<sup>11</sup> and reviewed by dermatologists experienced in the field. The data were collected via a Web-based survey of previously registered

users of the International Hyperhidrosis Society website ([www.SweatHelp.org](http://www.SweatHelp.org)).<sup>10</sup> Website users were invited to participate via e-mail. The survey included 22 multiple-choice questions, some of which allowed multiple responses. Certain questions were gatekeepers for ensuing questions, allowing responders to skip inapplicable questions (eg, if a responder stated that he/she had never spoken to a medical professional about HH, no further questions regarding interactions with medical professionals were asked). Respondents self-identified as suffering with excessive sweating in order to participate in the study by providing an affirmative answer to Question 1 (Table 1; Supplemental Survey Instrument). In addition to basic demographic information, the remaining questions queried aspects of both current and past patient experience with symptoms, interactions with medical professionals, and treatments. Possible respondents were capped at 2,000, and this quota was reached within one day.

## RESULTS

### Patients

Of 28,587 survey invitations, a total of 5,042 recipients (17.6%) opened the e-mail, and 2,045 respondents provided an answer to Question 1. Of these, 1,985 (6.9%) self-identified as

TABLE 1.

### Questionnaire Items

1	Have you ever experienced excessive sweating?
2	Where do you sweat excessively, and approximately how old were you when you first noticed it?
3	Do your relatives sweat excessively?
4	Has your sweating lessened as you have gotten older?
5	For each area that you sweat excessively, how would you rate the severity?
6	What time of year does your sweating bother you the most?
7	Rank the areas of your life that have been impacted by excessive sweating. (Use N/A if sweating has not impacted an area)
8	Have you ever spoken to a medical professional about your excessive sweating?
9	What type of medical professional did you speak with? (Check all that apply)
10	How many years did you experience excessive sweating before you spoke with a medical professional about it?
11	Has a medical professional ever diagnosed you with hyperhidrosis?
12	Who provided your FIRST diagnosis of hyperhidrosis?
13	What treatment was recommended to you by the medical professional(s) you asked?
14	Have you ever been treated for hyperhidrosis?
15	What treatments have you tried? (Check all that apply)
16	How satisfied were you with the treatments you have tried?
17	Why haven't you tried any treatments for hyperhidrosis?
18	What treatments were recommended by the medical professional but you decided not to try? (Check all that apply)
19	Why have you never spoken with a medical professional about your excessive sweating? (Check all that apply)
20	In what US geographic area do you primarily reside?
21	In what year were you born? (enter 4-digit birth year; for example, 1976)
22	What is your gender?

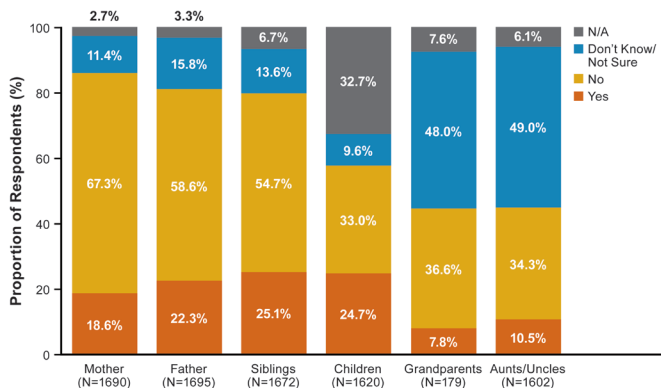
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**FIGURE 1.** Excessive sweating among family member.



N=1860 total respondents  
Question 3: Do your relatives sweat excessively?  
N/A, not applicable

having HH (ie, answered 'yes' to the following: Have you ever experienced excessive sweating?) and continued the survey. Regional distribution of respondents was relatively uniform (27.1% Northeast, 23.9% Southeast, 16.5% West, 12.0% Southwest, 20.5% Midwest), and nearly three-quarters (72.7%) of respondents were female. Most respondents (75.6%) were >31 years of age. Compared with rates of HH expected in the general population, a high percentage of respondents (between 18.6% and 25.1%) reported an immediate family member (parent, child, or sibling) with excessive sweating, consistent with an underlying genetic component to primary HH (Figure 1).

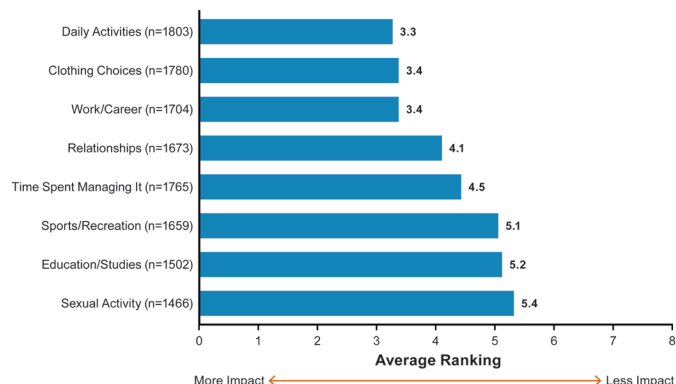
### Symptoms and Impact on Daily Activities

The most frequently reported body areas with excessive sweating were underarms (67.7%), hands (64.6%), and feet (64.4%); in each case, the majority of patients had noticed symptoms before the age of 18 years. When asked to categorize the severity of their HH and impact to their daily activities, more than half of respondents reporting excessive sweating of the underarm (52.1%), hands (66.3%), and/or feet (61.2%) stated that their sweating is barely tolerable/intolerable and frequently/always interfered with daily activities (ie, Hyperhidrosis Disease Severity Scale [HDSS] grade 3 or 4).<sup>12</sup> Based on an average rank score (range, 1 to 8, with lower scores indicating a greater impact), the top three areas impacted by excessive sweating were daily activity (average rank 3.3), clothing choices (average rank, 3.4), and work/career (average rank, 3.4; Figure 2).

### Interactions With Medical Professionals

A total of 89.5% of respondents reported speaking to a medical professional about excessive sweating, usually a dermatologist (76.7% of respondents) and/or a primary care professional (72.2% of respondents). Of the 79.1% of respondents who had been diagnosed, about half (49.3%) were first diagnosed by a

**FIGURE 2.** Rank impact of HH on patient activities.<sup>a</sup>



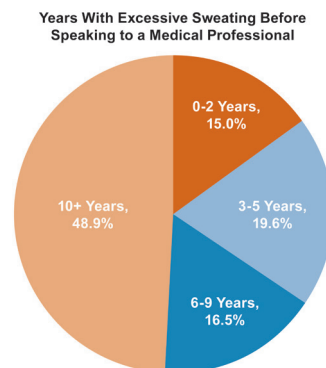
N=1860 total respondents; individual category 'n' values denote the number of patients who did not rank the category as "N/A"  
Question 7: Rank the areas of your life that have been impacted by excessive sweating (use N/A if sweating has not impacted an area)  
Ranked 1-8 by weight average rating; 1 [highest impact] to 8 [lowest impact]  
N/A, not applicable

dermatologist. Despite the high number of respondents seeking medical attention, nearly half (48.9%) experienced excessive sweating for 10 or more years prior to seeking medical help, and the majority (85.0%) let excessive sweating continue for at least three years (Figure 3).

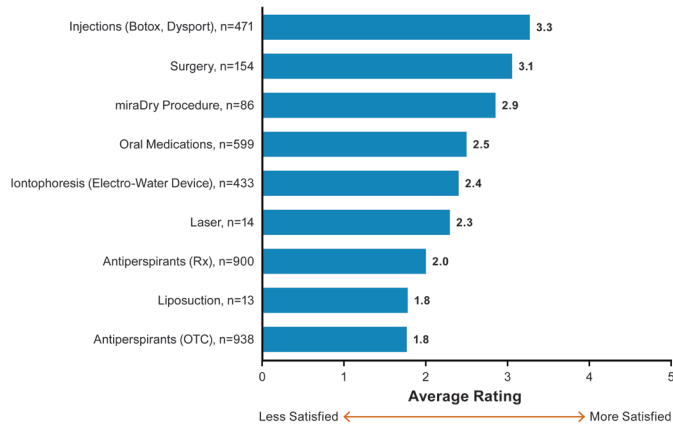
### Treatment Satisfaction

In this survey, 87.2% of respondents had received treatment for HH. The most commonly reported treatments (>15% of respondents) were prescription antiperspirants (78.0%), over-the-counter (OTC) antiperspirants (77.7%), oral medications (53.3%), injections (eg, botulinum toxin) (41.0%), and iontophoresis (38.1%). Among respondents who had not received treatment, 38.5% were not sure of the reason, 32.0% reported that they couldn't afford the recommended treatment,

**FIGURE 3.** Incidence of respondents reporting a delay in seeking medical help.



N=1661 total respondents  
Question 10: How many years did you experience excessive sweating before you spoke with a medical professional about it?

**FIGURE 4.** Patient satisfaction with HH treatment.<sup>a</sup>

N=1132 total respondents; individual category 'n' values denote the number of patients who did not rank the category as "N/A"

Question 16: How satisfied were you with the treatments you have tried? (use N/A if you have not used a given treatment option)

<sup>a</sup>Ranked 1-5 by weighted average rating; 1 [strongly dissatisfied], 2 [dissatisfied], 3 [neither dissatisfied nor satisfied], 4 [satisfied], 5 [strongly satisfied]

HH, hyperhidrosis; N/A, not applicable; OTC, over-the-counter; Rx, prescription

and 23.1% did not like the recommended treatment. Patients were the least satisfied (scores 2.0 or lower; range 1 to 5, with lower scores indicating greater dissatisfaction) with prescribed and OTC antiperspirants as well as liposuction (Figure 4).

## DISCUSSION

Survey results provided here expand on previously reported data that characterize the patient experience in HH. As previously reported,<sup>11</sup> the body areas most frequently affected by excessive sweating were underarms, hands, and feet (each >60.0%). This is a more uniform distribution than observed by Doolittle et al, in which a much lower overall occurrence of palmar (40%) and plantar (38%) sweating was reported.<sup>2</sup> Family history of excessive sweating was also queried. In this survey, participants reported a comparatively higher rate of HH than what would be expected in the general population. This is consistent with genetic studies that support HH as a genetic disorder with autosomal dominant mode of transmission, incomplete penetrance, and variable phenotype.<sup>13,14</sup>

Previous literature suggests that patients tend to wait 10 or more years before seeking treatment for primary HH,<sup>7</sup> and the observations from this survey reinforce that finding. In this study, 48.9% of respondents reported a delay in seeking medical treatment of >10 years after the initial appearance of HH symptoms, and 85.0% reported a delay of >3 years. Better patient education—both in terms of reinforcing HH as a legitimate medical condition and highlighting the availability of new and effective treatments—may reduce this delay. HH also encompasses a broad spectrum of patients, and each patient makes different lifestyle modifications that may not include seeking professional treatment. The results of this survey

do not make clear whether the ongoing presence of symptoms observed was related to lack of treatment or worsening disease.

HH impacts all aspects of life queried in this survey. The greatest impacts were observed for daily activity, clothing choices, and work/career. However, the average impact rank for all categories surveyed fell between a relatively small range (3.3 and 5.4; lower values indicate higher impact), suggesting a broad impact of HH on daily activities, a variety of clinical presentation, and/or individual perceptions of lifestyle disruption. These findings are consistent with the wide spectrum of HH clinical presentations observed in patients.

Patient satisfaction rates with currently available treatments observed in this study suggest a significant unmet need in therapeutic options. Further, the satisfaction rates observed in this survey do not correspond to the rate with which those treatments are prescribed or with objective measures of efficacy. Respondents were most satisfied with botulinum toxin injections, yet these are not often offered; antiperspirants are the most prescribed treatments, and patient satisfaction with these treatments was low. Potential new treatments for primary HH on the horizon currently include topical glycopyrronium tosylate (formerly DRM04), THDV-102, and BBI-4000. Glycopyrronium tosylate is an anticholinergic agent formulation for once-daily, topical administration that has demonstrated clinically meaningful improvements in sweating severity and quality of life (as assessed by the Dermatology Life Quality Index) in patients with primary axillary HH in two phase 3 vehicle-controlled, randomized, clinical trials.<sup>15</sup> THDV-102 is a twice daily, fixed-dose, oral combination of oxybutynin and pilocarpine that was shown to limit sweating and reduce dry mouth compared to taking oxybutynin alone in a phase 2 clinical trial in primary focal HH.<sup>16</sup> BBI-4000 (sofipronium bromide) is a topical anticholinergic with phase 2b study results in patients with axillary HH.<sup>17</sup>

Although the HDSS is used widely in clinical studies, it is not considered by the FDA to be suitable for use as an endpoint in clinical studies in support of product approval and/or labeling.<sup>18</sup> New measures for patient-reported outcomes have been recently developed, such as the Axillary Hyperhidrosis Patient Measures (AHPM), which include the 4-item Axillary Sweating Daily Diary to assess axillary sweating severity, impact and bothersomeness<sup>19</sup>; however, until such tools have been implemented in a range of studies, surveys offer important insight into patient experience. Given the level of severity reported within this survey and the associated impact to daily life, the delay in seeking professional medical treatment is remarkable. Furthermore, combating this delay in seeking treatment is of particular importance given the established association between HH and mental health, particularly social anxiety and depression.<sup>6,20-22</sup> Recognition of HH as a true medical condition

is often disputed despite recognized International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) codes. Perhaps if HH was legitimized as a medical condition, rather than a cosmetic one, treatment would be more accessible and the delay in seeking medical care would be reduced.

Self-reported surveys can be a useful tool to reveal patient insight and experience, but it should be noted that the survey was completed by US IHHS newsletter registrants, which likely reflect a highly-motivated population that may not be representative of HH patients overall. In addition, most of the patients in the survey were over the age of 30 years. HH is a condition that impacts pediatric and adolescents as well, so further study into challenges that may be unique to these age groups is warranted. Finally, no clinical tests were used to confirm HH diagnosis, raising the possibility of non-HH participants in the sample.

Despite these caveats and other inherent survey-based limitations, such as recall bias, this study adds important clinical insight for the underserved HH patient population. Each patient journey is unique and may start long before a HH diagnosis is even established, highlighting the need to increase HH awareness among the public and clinicians, to reduce stigma associated with the condition, to accelerate an accurate diagnosis, and to encourage the implementation of treatment strategies as soon as possible.

## DISCLOSURES

Dr. Glaser is a consultant, advisory board and/or principal investigator for: Dermira, Inc. Dr. Hebert is a consultant, advisory board and/or principal investigator for: Dermira, Inc. Lisa Pieretti is an employee of the International Hyperhidrosis Society. Dr. Pariser is a consultant, advisory board and/or principal investigator for: Abbott Laboratories, Amgen, Bickel Biotechnology, Biofrontera AG, Celgene Corporation, Dermavant Sciences, Dermira, Inc., DUSA Pharmaceuticals, Inc., Eli Lilly and Company, LEO Pharma, US, Merck & Co., Inc, Novartis Pharmaceuticals Corp., Novo Nordisk A/S, Ortho Dermatologics, Peplin, Inc., Pfizer, Inc., Photocure ASA, Promius Pharmaceuticals, Regeneron, Sanofi, Stiefel a GSK Company, TheraVida, and Valeant Pharmaceuticals International.

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