

Characterization of Disease Awareness and Coping Strategies in Primary Focal Hyperhidrosis: Qualitative Focus Group Results in Children, Adolescents, and Young Adults

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BACKGROUND

- Hyperhidrosis is defined as uncontrollable and excessive sweat production beyond what is necessary to maintain thermal regulation.¹
- Primary focal hyperhidrosis affects an estimated 4.8% of the total U.S. population and approximately 2% of those under the age of 18; more recent data include findings from an online survey in the U.S. showing that roughly 17% of teens report experiencing excessive sweating, with nearly 75% of those characterizing it as leading to major or moderate daily impairment.^{1,2}
- There is a paucity of scientific studies in hyperhidrosis (especially in pediatric populations) as well as a general lack of awareness of hyperhidrosis as a bona fide medical condition and an underappreciation for the extent of burden caused by the disease.
- Here, we report results of a qualitative research collaboration, utilizing interviews and focus groups in children, adolescents (and their caregivers) and young adults to gather insights on experiences and perceived gaps in available resources for hyperhidrosis support, diagnosis and coping strategies. Additional findings from this study with respect to quality of life impact are included within a separate poster at this SPD 2020 Annual Meeting (#61: "Quality of Life Impact of Primary Focal Hyperhidrosis: Qualitative Focus Group Results in Children, Adolescents, and Young Adults").

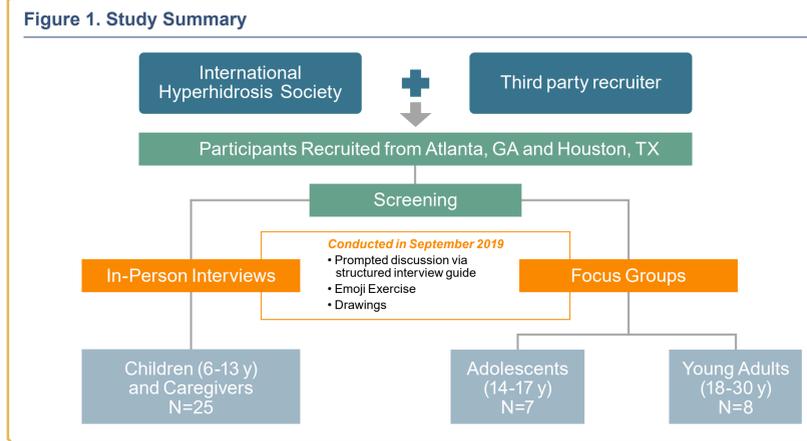
METHODS

Study Design and Participants

- Figure 1** summarizes the study features, which included a deductive qualitative design supported by in-person interviews in children with excessive sweating and their caregivers (ages 6-13 years) as well as in-person focus groups (no more than 4 participants per group) with adolescents (ages 14-17 years) and young adults (ages 18-30 years). Adult participants were asked to reflect on their experiences living with hyperhidrosis when they were younger.
- Participants were recruited by third-party recruiters and a main hyperhidrosis patient advocacy organization (the International Hyperhidrosis Society [IHHS; www.Sweathelp.org]).
- A clinical diagnosis of moderate-to-severe hyperhidrosis, self-identification of excessive sweating, or identification of likely primary hyperhidrosis via targeted screening questions was required.^{3,4}
- Screening questions were hierarchical (i.e., a minimum number of hyperhidrosis-indicating responses were required for more detailed questioning).
 - Participants 17 years of age or less required caregiver consent.
- Participants underwent an initial, online pre-screening followed by a validation phase.
 - Eligibility was validated via phone, during which a trained recruiter confirmed online responses for study inclusion criteria.
 - Compensation was offered for time spent in interviews.

Data Collection

- Data were collected during 90-minute in-depth interviews or small focus groups conducted in September 2019 in Houston, Texas and Atlanta, Georgia.
- Professional moderators using a structured interview guide led the discussion to understand the treatment experience and awareness of disease.
- All interviews and focus groups were recorded and transcribed and analyzed.



RESULTS

Study Participants

- Characteristics of the 40 participants are described in **Table 1**.
 - Among 25 respondents in the 6-9 year group, 12 were caregivers.
 - Participants reported a wide range in the age of onset.
 - Most participants experienced excessive sweating in multiple focal areas.
 - Areas with excessive sweating were generally consistent with focal hyperhidrosis, including palmar (96%), axillary (86%), plantar (86%), craniofacial (61%), back (61%), and inguinal (18%) regions.

Table 1. Participant Characteristics

		N=40		
		Children (6-13 y) ^a and Caregivers n=25	Adolescents (14-17 y) n=7	Young adults (18-30 y) n=8
% Male		6/13 (46%)	2/7 (29%)	4/8 (50%)
Mean Age (years)		10	16	25
Mean Age of Onset		7	11	16
Areas of Hh involvement, n (%)	Palmar	13 (100%)	6 (86%)	8 (100%)
	Plantar	10 (77%)	6 (86%)	8 (100%)
	Axillary	11 (85%)	5 (71%)	8 (100%)
	Craniofacial	12 (92%)	4 (57%)	1 (13%)
	Back	9 (69%)	4 (57%)	4 (50%)
	Inguinal (groin)	2 (15%)	2 (29%)	1 (13%)

^aIncludes 13 children, including one set of twins, and 12 caregivers

Disease Awareness

- Hyperhidrosis disease awareness among these participants was minimal, though some (n=6) had received a medical diagnosis of hyperhidrosis (**Figure 2**).

Figure 2. Lack of hyperhidrosis awareness.

Lack of Disease Awareness

- A minority of participants (n=6) were aware of the term "hyperhidrosis," with a few participants providing vague mentions of "hyper-something" or "something-hidro" in their responses.

Limited HCP Engagement

- Less than half of the sample had consulted a pediatrician (n=8 of 20 pediatric participants), and even fewer (n=3 of 28 participants with excessive sweating) reported having seen a dermatologist.
- Participants often discussed these symptoms with their healthcare providers as part of an annual exam or during a visit for another reason as opposed to one specifically related to excessive sweating.

Suboptimal Treatment

- Among the 28 participants with excessive sweating (not caregivers), only one had received a prescription for hyperhidrosis treatment.

- Of note, caregiver feedback was not systematically collected; however, moderators did note a reluctance by some caregivers to 'medicalize' the condition. Several caregivers in the study (n=6) also suffer from hyperhidrosis themselves and are more conscious of the impact. While some of these were very supportive and understanding, other caregivers tended to downplay the impact of excessive sweating to protect their child's self-esteem.

Management Strategies

- The most common coping strategies described by participants in this study generally fell into one of three categories: adapting daily living behaviors, adding hygiene steps, or changing social interactions (**Figure 3**).
 - Respondents noted the need to plan ahead to account for a change of clothes and report making specific clothing choices (eg, loose-fitting, colors that won't show sweat stains).
 - In addition, children note particular school behaviors that are adapted in order to minimize their worry (eg, avoiding raising their hand in class, bringing supplies with them to absorb sweat, or minimizing activity in gym class).

Figure 3. Management Strategies Used Across Hyperhidrosis Sufferers.

ADAPTING DAILY LIVING BEHAVIOR	ADDING HYGIENE STEPS	CHANGING SOCIAL INTERACTIONS
<p>Clothing choices</p> <p>Clothing choices highly impacted:</p> <ul style="list-style-type: none"> Loose clothing; cotton or dry-fit fabrics; light or dark colors that don't show sweat/stains Absorbent socks; avoiding plastic sandals Washing shoes, inserts or frequent replacements Wearing layers even in hot weather to hide sweat 	<p>General Hygiene</p> <ul style="list-style-type: none"> Shower 1-3 times/day Frequent washing, showering, and wiping Increased use of antiperspirants and powders Ensure access to hygiene aids throughout day (spare antiperspirant / wipes / towels, and clothes) Washing shoes, buying inserts, replacing frequently 	<p>Keeping clothes clean</p> <ul style="list-style-type: none"> Spare clothes kept in locker/ bag / car from older childhood onwards Order of extra school uniforms High laundry burden from regular washing of multiple clothing changes each day Mentions of wearing maxipads / napkins under armpits to soak up sweat
		<p>Isolating Behaviors</p> <ul style="list-style-type: none"> Older children (4th - 5th and 6th - 8th Grade) and adolescents avoid putting up hand in class / raising arms in public; avoid joining in activities, avoid high fives or other hand contact. Older children / adolescents (esp. females) may avoid activity at recess / PE to avoid sweating (though others like physical activity as sweating is "permissible")

CONCLUSIONS

- Disease awareness in this study was low, and participants had minimal experience with treatment beyond basic coping mechanisms, which underscores the need to raise awareness of this disease and of available treatment options including among healthcare professionals.
- Taken together, these results emphasize that there is clearly a need to raise awareness among pediatric sufferers and caregivers and to establish hyperhidrosis as a bona fide medical condition in the youngest patients, particularly given that onset is often during the pediatric/adolescent years, and effective treatment options are available and can improve symptoms and quality of life.⁴⁻⁶
- The value of the current study is that it represents the required first step for subsequent systematic data collection in pediatric hyperhidrosis patients, data that are sorely needed to guide optimal management and alleviate suffering and disease impact of these patients. The results of this research will inform the development of a large, quantitative survey to further understand the awareness and impact of hyperhidrosis on a young person's life (see also SPD 2020 Poster #61: *Quality of Life Impact of Primary Focal Hyperhidrosis: Qualitative Focus Group Results in Children, Adolescents, and Young Adults*).

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ACKNOWLEDGEMENTS

This study was funded by Dermira, Inc., a wholly-owned subsidiary of Eli Lilly and Company. Medical writing support was provided by Prescott Medical Communications Group (Chicago, IL). All costs associated with development of this poster were funded by Dermira, Inc., a wholly-owned subsidiary of Eli Lilly and Company.

DISCLOSURES

ZPR: Advisory Board/Panel – Cassiopaia, Pfizer, Medscape; Consultant – Brickell Bio, Cassiopaia, Demira Inc., a wholly-owned subsidiary of Eli Lilly and Company, Pfizer; Principal Investigator of Research Grant – Anacor, Celgene, Galderma, Regeneron/ Sanofi- Genzyme, Merck & Co. Abbvie; Speaker's Bureau Promotional Education – Demira Inc., a wholly-owned subsidiary of Eli Lilly and Company, International Hyperhidrosis Society, Pfizer, PRIME, Regeneron/ Sanofi- Genzyme; LJP: Employed as Executive Director of IHHS; Consultant – Candesant, Dermira Inc., a wholly-owned subsidiary of Eli Lilly and Company, AW: Consultant – Dermira Inc., a wholly-owned subsidiary of Eli Lilly and Company; JP: Consultant – Dermira Inc., a wholly-owned subsidiary of Eli Lilly and Company; KKG and TD: Employees of Dermira, Inc. a wholly-owned subsidiary of Eli Lilly and Company; AAH: Research grants paid to UTHealth McGovern Medical School – Dermira Inc., a wholly-owned subsidiary of Eli Lilly and Company, Brickell, Allergan; Honoraria – Dermira Inc., a wholly-owned subsidiary of Eli Lilly and Company, Brickell GSK; Data Safety Monitoring Board – GSK