Quality of Life Impact and Awareness of Primary Focal Hyperhidrosis in Children and Adolescents

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BACKGROUND

- Hyperhidrosis is defined as uncontrollable and excessive sweat production beyond what is necessary to maintain thermal regulation and 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]
- In general, there is a lack of awareness of hyperhidrosis as a bona fide medical condition and an underappreciation for the extent of burden caused by the disease.[3-7] Though primary focal hyperhidrosis typically has a childhood/adolescent onset, very few studies exist on the impact and burden of the disease in younger patients compared with adult patients.
  - Survey results show that nearly half of all those affected report waiting 10 or more years before seeking medical help for their excessive sweating.[8]
  - This delay in seeking help occurs despite the fact that those suffering with hyperhidrosis have a decreased quality of life, including social embarrassment and negative effects on emotional/mental health and limiting daily activities.[1,8-11]
- Here, we report results of a qualitative research collaboration, utilizing interviews and focus groups in children, adolescents (and their caregivers) and young adults to characterize the quality of life impact in this understudied population. Additional findings from this study provide insights on experiences and perceived gaps in available resources for hyperhidrosis support, diagnosis and common management strategies.

METHODS

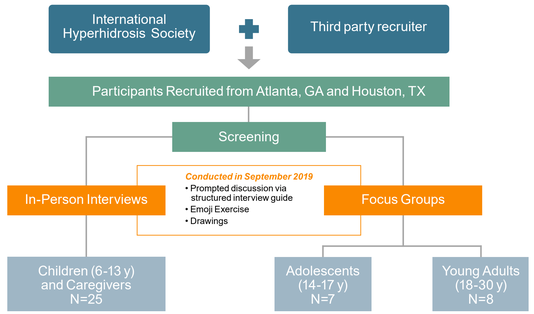
Study Design and Participants

- **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 patient 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.[12,13]
  - 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 emotions, perceptions, and adjustments made with respect to living (or caring for someone) with hyperhidrosis as well as treatment experience and awareness of the disease.
- All interviews and focus groups were recorded and transcribed for subsequent content, linguistic, and thematic analysis to identify and categorize topics, ideas and patterns of meaning that were repeated.
- Interviewers led an emoji exercise, where respondents could select a visual cue in the form of an emoji icon to best capture how hyperhidrosis makes them feel; participants also completed drawings.

Figure 1. Study Summary



RESULTS

Study Participants

- Characteristics of the 40 participants are described in **Table 1**.
  - Participants reported a wide range in the age of onset.
  - Most participants reported experiencing 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%)

[a]includes 13 children, including one set of twins, and 12 caregivers

Quality of Life Impact (Children, Adolescents, Caregivers, and Young Adults)

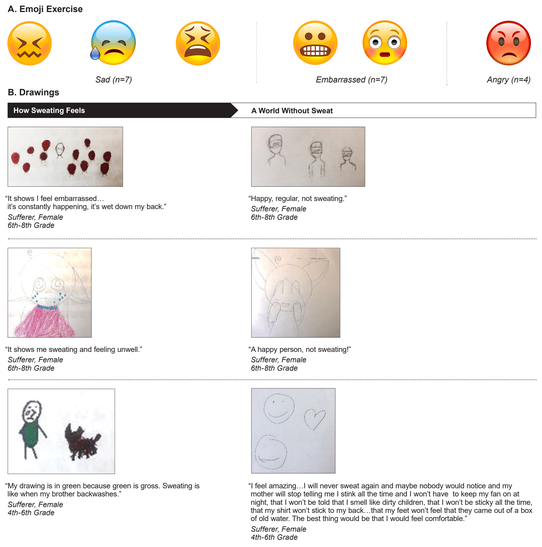
- Age-dependent trends emerged with respect to quality of life impact, concurrent with progression through different life phases (**Figure 2**).
  - Young children (1st – 3rd grade) primarily demonstrate physical and functional impairment related to daily activities.
  - Among 4th to 8th graders, physical impact increases as sweating worsens and expands to additional regions, resulting in significant functional impairment in school (difficulty holding pencils, using technology that requires tactile imprint).
    - Importantly, children in this age group have grown more conscious of social norms, leading to an increased social/emotional impact and reduced academic, extracurricular, and social activity participation.
  - In the high school age group, all quality of life domains are negatively impacted, though financial impact was not as notable.
    - This group was most likely to report teasing/bullying from their peers and report increases in anxiety.
    - Social situations (dating, dances, extracurricular activities) increase anxiety, worry, embarrassment, anger, shame, and frustration and may lead to restrictive or isolating adaptive behaviors.

Figure 2. Quality of Life Impact Varies Across Age Groups

Domain Impacted	Grades 1-3	Grades 4-5	Grades 6-8	Grades 9-12	Post High School
Physical	✓	✓	✓	✓	✓
Functional	✓	✓	✓	✓	✓
Social	Limited	✓	✓	✓	✓
Emotional	Limited	Limited	✓	✓	✓
Financial	Limited	Limited	Limited	✓	✓
In Their Own Words					
Representative Quotes	*"There is a lot of sweat on my feet, my hands, my face and body".* *"I don't like taking shoes off in front of a lot of people, it just wears me out, my feet are just gross."*	*"I check if anyone is around and hide it so that no one can see, make sure it's not obvious that I am sweating."* *"When my feet are sweating and I don't have socks on it is hard to walk around and it feels like I am walking on water."*	*"When I try to answer something in class I have to find a different way of putting my hand up [to hide damp armpits]…it's really awkward."* *"I don't want to talk to my friends about it because I don't think they would understand."*	*"My best friends, they crack a joke with me about it. They're like, 'You look gross', or whatever, 'She's sweaty!'"* *"…what's going to happen if I come over there and I shake their hand, or they're going to want to go in for a hug, if I'm thinking about it, like leading up to it, that's the worst."*	*"I change my clothes multiple times a day so I can control everything - I dot Last night and today I've worn three different shirts and three different pairs of underwear because I just want to make sure I'm okay, yes, it's a self-conscious thing."* *"I've got to have a desk job because I can't be sweating on people. That helps more, actually, because you don't have to interact with as many people."*

- The burden of hyperhidrosis does not appear to be diminished in adulthood.
  - Adults report limiting situations that make them sweat more (e.g., meeting new people, outdoor concerts).
  - Functional impacts evolve as they are confronted with professional interactions (shaking hands, wearing business attire, working in an office, interacting with new people), which in turn may have a negative financial impact as a result of adapting professional choices and behaviors in order to navigate the disease.
- Across all age groups, language and visual depictions of associations with sweating were negative and dramatically described (e.g., damp, embarrassing, gross, disgusting).
  - This negative association was visualized through an emoji exercise in which the most common emotions across all age groups are sadness, embarrassment and anger (**Figure 3A**).
  - In addition, the negative association was candidly represented through drawing, even among the youngest patients (**Figure 3B**). .

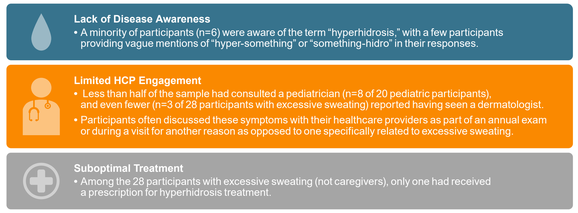
Figure 3. Negative Association of Sweating Among Children



Disease Awareness

- Hyperhidrosis disease awareness among these participants was minimal (Figure 4).

Figure 4. Lack of Hyperhidrosis Awareness

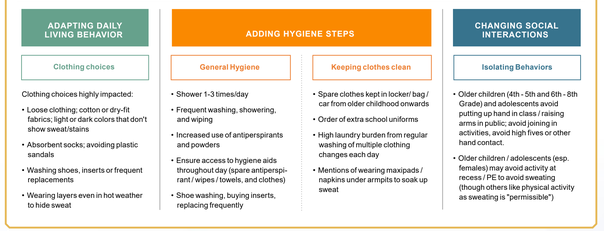


- Of note, caregiver feedback was not systematically collected; however, moderators did note a reluctance by some caregivers to 'medicalize' the condition. Several caregivers in the study (n=6) also suffer from hyperhidrosis themselves and are more conscious of the impact. While some of these were very 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 5).
  - 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 towels to absorb sweat, or minimizing activity in gym class).
  - Though data were not systematically collected, gender-specific differences were most evident among adolescents with respect to physical activity, with female adolescents/older children more likely to comment on restricting their physical activity than male respondents.
  - In addition, adolescent female sufferers appeared more likely than male counterparts to experience a high emotional burden due to self-esteem issues (e.g., concerns about appearance, limitations in clothing choices) and were more likely to carry additional hygiene products with them.

Figure 5. Management Strategies Used Across Hyperhidrosis Sufferers



CONCLUSIONS

- One of the main objectives of this study was to better understand the impact to individual quality of life domains in the youngest hyperhidrosis patients. To our knowledge, this study is the first to describe quality of life impact across age groups in a pediatric population who suffer with excessive sweating.
- The interview and focus group data show that there is an evolution of quality of life impact, with a clear impact within the functional domain at even the earliest ages and increasing social/emotional burden developing over time. This phenomenon has not been documented previously in the literature.
- 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, particularly given that effective treatment options are available and can improve symptoms and quality of life.[14-16]
- The value of the current study is that it represents a first step for subsequent systematic data collection in pediatric hyperhidrosis patients, data that are sorely needed to guide optimal management of these patients. The results of this research are currently being used to inform the development of a large, quantitative survey to further understand the awareness and impact of hyperhidrosis on a young person's life.

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