Quality of Life Impact of 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]
- Hyperhidrosis is underdiagnosed by healthcare providers and underrecognized as a chronic medical condition.[3-7]
  - 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]
  - 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.
- 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 with respect to disease awareness and common management strategies are included within a separate poster at this SPD 2020 Annual Meeting (#14: "*Characterization of Disease Awareness and Coping Strategies in 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.
  - 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.
- All interviews and focus groups were recorded and transcribed and analyzed 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 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] or 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 (%)	Palmarx	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
Hh, hyperhidrosis

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

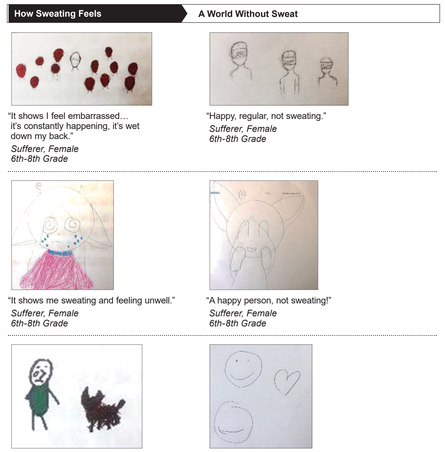
Aspect of Life Affected	6–8 Year Group (n=4)	9–13 Year Group (n=9)	14–17 Year Group (n=7)
Physical	Feeling uncomfortable; difficult regulating temperature; sleep disruptions	Sweating frequency and areas affected increase with age; increased discomfort	Physical impact increases
Functional	Difficulty grasping objects; impact on running/ shoe type; additional hand washing; water drinking, bathing and clothing/bedding changes	Dexterity difficulties with fine objects/smooth surfaces (pens/door knobs); more time spent tending to hygiene; sweat marks on school papers can affect academics; may minimize physical activities, affecting fitness	Dexterity difficulties and attention to hygiene continues; independence/self-care increases, along with formative decisions about sweat management with evolving developmental situations/milestones; increased efforts to hide sweating
Social	Limited impact	Begin to feel "different" and socially isolated; decrease social interactions; worried about what others see	Social isolation and worries about the opinions of peers increases; more bullying; new social opportunities (dances/dating) avoided
Emotional	Limited impact	Frustration over lack of control; anxiety related to sweat triggers; also feel sadness, embarrassment, shame, irritation, and anger	Increased anxiety; new stressors increase HH triggers; new coping strategies evolve (humor/deflection) to deal with bullying; confidence and self-esteem negatively impacted
Financial	Limited impact	Caregivers purchase more advanced hygiene products and special clothes	Part-time work choices and participation in internships may be limited
In their words	"I've never been keen on sport and sweating is one of the reasons why… because I want to be able to focus. I would worry if my feet, hands and nose would start sweating." "It don't like taking shoes off in front of a lot of people, it just wears me out, my feet are just gross." "There is a lot of sweat on my feet, my hands, my face and body."	"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 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'm walking around, it feels like I'm walk around and it feels like I am walking on water."	"Sometimes, because when you're sweating and you stain your clothes, it can be distracting if you're trying to engage with others because you notice their eyes are kind of just looking at your stained clothes." "…what's going to happen if I come over there and I shake their hand, or they're going to remember that I'm the girl that's sweaty, it's like beading up in it, that's the worst." "My best friends, they crack a joke with me about it. They're like, 'You look great,' or whatever, 'She's sweaty!'"

- 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, utilizing touch screen technology, and 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 were sadness, embarrassment and anger (**Figure 3A**).
  - In addition, the negative association was candidly represented through drawing, even among the youngest participants (**Figure 3B**).

Figure 3. Negative Association of Sweating Among Children

A. Emoji Exercise

B. Drawings



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 sufferers. To our knowledge, this study is the first to qualitatively characterize 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 the earliest ages and increasing social/emotional burden developing over time. This phenomenon has not been documented previously in the literature.
- Importantly, findings from this qualitative research are currently being applied to the development of a large-scale, quantitative survey designed to systematically collect data specifically on quality of life impacts as well as a characterization of the overall experience among the youngest patients with primary hyperhidrosis (see also SPD 2020 Poster #14: *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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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 – Cassiopeia, Pfizer, Medscape; Consultant– Brickell Bio, Cassiopeia, 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

Poster presented virtually at the 45th Annual Meeting of the Society for Pediatric Dermatology • July 10–12, 2020