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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ABSTRACT

Background: The literature on primary focal hyperhidrosis in children, adolescents, and young adults is limited. This study was performed to characterize disease awareness and coping strategies from the perspective of children, adolescents, and young adults with focal hyperhidrosis in a qualitative focus group setting.

Methods: Study design and participants: A mixed-method study design was employed. Participants underwent an initial, online screening followed by a validation phase. Recruitment occurred from September to October 2019. Participants included 14 children, 12 adolescents, and 16 young adults, totaling 42 participants (N=40) from 34 states. All interviews and focus groups were recorded and transcribed and analyzed.

Results: Among the 28 participants with excessive sweating (N=3 of 28 participants with excessive sweating) reported limited HCP engagement and care. Participants often discussed their experiences with their healthcare providers as part of an annual exam or during a visit for another indication and were not specifically targeted to receive excessive sweating assessments.

Suboptimal Treatment

Among the 28 participants with excessive sweating (N=8 of 20 pediatric participants), and even fewer (n=1 of 8 adolescents and young adults) received a medical diagnosis of hyperhidrosis.

Disease Awareness

Hybrid H disease awareness among these participants was minimal, though some (n=4) had received a medical diagnosis of hyperhidrosis (Figure 2).

Lack of Disease Awareness

Among the 20 participants with excessive sweating, 5 (25%) stated they had never heard of hyperhidrosis. The majority (n=12 of 20) did not know the term “hyperhidrosis,” with a few participants providing vague mentions of “hyper-something” or “something-hidro.”

Suboptimal Treatment

Most participants (n=14 of 28) felt a need for better treatment options, and the majority (n=13 of 28) stated that they had a need for more information on hyperhidrosis treatment.

CONCLUSIONS

• Disease awareness in this study was low, and participants had minimal treatment experience with the use of different coping mechanisms, which underscores the need for increased 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 of the condition, necessary and important to end the suffering and disease impact that this condition has on patients.

• 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 likely to be needed to support managed care decisions and well-researched, evidence-based guidelines of these patients.

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REFERENCES


