women with anticipatory guidance, support, and education, emphasizing the importance of a genetic counseling presence in Bleeding Disorders clinics. Community immersion has also been extremely beneficial for mothers, as family members and peers serve as a source of social and educational support. Roughly half of the women did not feel guilt, which serves as a testament to support organizations and their role in creating a highly informed, connected, supportive, and resilient community.

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OP032

Communication practices of parents and unaffected sibling needs in families impacted by a diagnosis of Angelman syndrome

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Introduction: Angelman syndrome (AS) is a rare, neurodevelopmental condition affecting approximately 1 in 15,000 individuals. To date, one study evaluated the relationship between the unaffected sibling and child with AS; however, no research has analyzed parental communication about AS with unaffected siblings and these siblings' needs. This study aimed to understand the nature of communication between parents and unaffected siblings including if discussion about AS had occurred and the content discussed. The study also evaluated the unaffected siblings' knowledge and perception of AS.

Methods: The research team created two novel electronic surveys (parent, child) using the University of Colorado's Research Electronic Data Capture tool. Survey content and questions were based on detailed literature reviews, personal clinical experience, and input from other AS professionals. The survey consisted of closed-ended questions (true/false, multiple choice, Likert scale ratings) used for statistical analysis to describe the parent and sibling experiences, as well as open-ended free text questions used for qualitative analysis to capture emergent themes. Participants provided consent and siblings' assent to participate prior to beginning the survey. Participants were recruited for this international electronic survey study through Colorado Children's Hospital AS Clinic, online support groups and social media platforms. Inclusion criteria were families with a child diagnosed with AS and at least one unaffected child aged five years or older. Descriptive statistics and frequency tables were utilized to calculate mean, range, percentages, and standard deviation. Pearson's correlations were used to examine associations between child age and knowledge of AS, and Pearson's Chi-square was used to calculate differences between parents and children on perceptions of the unaffected child's emotions regarding their sibling with AS. Open, inductive coding was used to capture novel, emergent themes directly from the data. We engaged in consensus coding to collectively develop the coding structure and assign units of meaning to all data. The team analyzed code frequencies and relationships between codes, reduced the data into categories, and finally developed broad overarching descriptive themes.

Results: One hundred twenty-four families consented to the study; 82 families met the criteria and completed the required surveys. The majority of parent respondents (94%) reported they had talked with their unaffected child about AS. Approximately half (42.9%) of parents reported the first conversation occurred when their unaffected child was 2-4 years old and 50% of parent respondents reported their child was the one to first initiate the conversation by asking questions. Five respondents (6%) reported they had not discussed AS with their unaffected child. Although all five parents reported they planned to discuss AS in the future, two parents reported they did not feel confident in their abilities to discuss AS.

No parents endorsed that they had communicated to their unaffected child reasons why their sibling with AS required more attention and care. Over half of parents (61%), reported it was difficult to give their unaffected child as much attention as their child with AS and 61% reported they were not able to spend enough one-on-one time with their unaffected child. Similarly, 50% of child respondents reported their sibling with AS received more attention from their parents and 50% expressed a desire for more one-on-one time with parents.

Seven multiple choice survey questions assessed unaffected siblings' understanding of AS. Twenty-seven percent of siblings answered all seven questions correctly. Correct answers did not correlate with sibling age (r (78) = .14, p =.224) and respondents with 100% correct answers ranged in age from 5 to 28 years old (M = 12 years old, SD = 6.74). Although the majority of parents reported they had discussed AS with their unaffected child, 34 siblings (41%) still had unanswered questions. Siblings answered many knowledge questions correctly, the majority (86%) also reported they still wanted to learn more about AS and 38 siblings (48%) reported they also wanted someone to talk to their classmates about AS. Open ended questions assessed siblings' perception of their sibling with AS. In response to the prompt: "Tell me about your sibling with AS", the majority (54%) described their sibling's positive characteristics, including a happy demeanor, affection, and successful completion of developmental milestones. Few child respondents (12%) solely discussed their sibling with AS negatively. Negative topics included behavior problems, attention seeking, and feeling disconnected. The remainder (34%) described a mix of both positive and negative characteristics in their siblings.

Conclusion: This study highlights the need for improved communication between parents and their unaffected children and emphasizes the importance of educational materials for unaffected siblings. Also, our study paves the way for further research on siblings of children with AS, and also for other rare diseases. Further studies might utilize focus groups of parents to understand parents' comfort level in delivering specific information and hesitations around certain topics related to AS. Sibling focus groups could elaborate on our findings by providing more in-depth information about sibling knowledge of AS, unanswered questions, and their perception of their siblings with AS. Lastly, our study identified several specific resources needed in the AS community. We propose the creation of a sibling toolkit that is distributed to all Angelman syndrome clinics. Ideas for toolkit content include children's books about AS, information on commonly asked sibling questions, and topics to discuss with siblings.

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