The Experiences of Parents of Children Who Stutter and Their Involvement in Support Groups

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Developmental stuttering is a communication disorder that typically begins between the ages of two and four and is usually preceded by a typical degree of fluency. While approximately 75% of children will not persist, the remaining are at increased risk of lifelong stuttering. Despite decades of research into the causes and implications of stuttering, it’s still a bit of an enigma. The effects of stuttering on caregivers of people who stutter (PWS) remains even more in the shadows. As compared to research regarding the caregiver experience in other disorders, research focusing on caregivers of PWS is startlingly sparse. Additionally, though many believe the same principles may be applied across disorders, the underlying experiences of caregivers of PWS are often fundamentally different. Factors that may contribute to the caregiver’s emotional distress include the stigma surrounding stuttering, outdated ideas that stuttering is caused by environmental factors, and a lack of knowledge of the disorder- with many communication professionals also feeling out of their depth regarding its treatment. Research is also lacking regarding protective factors for these caregivers. While the most frequent protective factor identified in other disorder research is social support, the first and most notable study done for parents who attend stuttering support groups was just completed in 2015 (Klein et al., 2015). While this study began to lay a solid foundation by investigating the experiences of parents of PWS and the impact of support groups, it did not provide detailed accounts or chronicle those experiences over time. The present study seeks to expand on this basis through the collection and analysis of in-depth narrative interviews with parents of children who stutter who have been active in support groups. What are the stories parents tell about their experiences having a child who stutters? What influence does a support group have in the development of these stories? It is our hope that engaging in rich discussions about the caregiver experience will not only improve our overall understanding of stuttering from multiple perspectives but will also push clinicians to actively involve the caregiver and subsequently built the most supportive environment for our clients.