

Exploring Parental Attitudes about Behaviors Seen in Their Children with Fragile X Syndrome

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Fragile X syndrome (FXS) is a triplet repeat disorder caused by an expansion of CGG repeats in the 5' untranslated region of the *FMR1* gene on the X chromosome. In addition to intellectual disability or learning delays, individuals with FXS can also have behavioral issues, including attention problems, hyperactivity, anxiety, aggression, impaired social interaction, and stereotypical movements. Compared to parents of children without a disability, parents of children with disabilities often experience higher levels of stress, particularly when their child had behavior problems. This has been seen in FXS. However, more research is needed to explore how parents feel about their child's specific behaviors. This study investigated what behaviors in FXS parents find to be the most problematic, how they cope with these behaviors, and what interventions have helped improve or end the behaviors. Parents identified anxiety, aggression, and attention problems as the most problematic behaviors seen in their children and stereotypical behaviors as the least problematic. When asked how they cope and how their life has been affected by their child's condition, many parents talked about the significant impact the behaviors had on their family. This impact was felt in many different aspects of their lives, ranging from financial difficulties and lost job opportunities to family and marital strife and the feeling of social isolation. Parents reported that reaching out to other parents of children with FXS and educating themselves about the condition allowed them to cope with the behaviors.