



Research Brief

A SUMMARY OF A PUBLISHED ARTICLE

Psychological Well-Being and Coping in Mothers of Youths with Autism, Down Syndrome, or Fragile X Syndrome

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Raising a child with a developmental disability can be stressful for parents. A parent's ability to cope with this stress varies and can have many implications for the mental health of the parent and the well being of the family as well. Most research has focused on parents of individuals with Down syndrome and autism, however. Less research has been conducted on mothers of individuals with fragile X syndrome.

This study compared the psychological well-being of mothers of adolescents and young adults, ages 10-23, with fragile X syndrome, Down syndrome, or autism. There were 22, 39, and 174 mothers for each group, respectively. The researchers wanted to: (1) find out whether there are differences in maternal psychological well-being for the three groups and (2) begin to understand the sources of these differences. By examining many different factors related to the mother's mental health and the behavior and characteristics of her child, the researchers were able to study in-depth many of the issues faced by these mothers.

This article included a thorough review of past research studies that examined parental coping in families of children who had Down syndrome, autism or fragile X syndrome. Several factors that past research has found to cause differences in how parents adjust to living with their child who has a disability were described:

Learning of the diagnosis

One major factor that can cause differences in

how parents adjust to living with their child who has a disability is the time that they receive the diagnosis. In most cases, Down syndrome is diagnosed prenatally or within hours of birth, whereas fragile X syndrome and autism often remain undiagnosed for years, which can be a source of stress.

Challenging behaviors

Many of the behaviors exhibited by individuals with fragile X syndrome are similar to those of youths with autism, which may lead to some similarities in the way that parents of both groups cope with the challenges they face. Some of these troublesome behaviors include hyperactivity, social anxiety, tantrums, and aggressive outbursts. All of these challenging behaviors can result in heightened stress for mothers.

Multiple children with special needs

In both fragile X syndrome and autism, there is a greater risk of having more than one child with a disability, which can also create more stress on parents and families.

Inheritance pattern

Biological mothers of individuals with fragile X syndrome carry either the premutation of fragile X or the full mutation themselves, which can complicate their reactions to many of the challenges they face. The researchers

“The period of adolescence and young adulthood may be especially challenging for parents because of the impending transition from school to work and a heightened concern about their son or daughter’s future.”

“It may also be helpful...to provide parents with respite and other forms of social support that may buffer some of the inevitable stress associated with [their children’s] behaviors.”

hypothesized that mothers may be at elevated risk for conditions such as anxiety, which can make raising a child with fragile X syndrome even more difficult.

This study investigated many of the ways that mothers of youth with fragile X syndrome and other disabilities react to stress. Many of the measures used in this study have shown differences in parental response depending on the disability. The Questionnaire on Resources and Stress assessed feelings of pessimism about a son or daughter’s future; the Positive Affect Index measured views on the quality of the parent-child relationship; the Center for Epidemiologic Studies Depression Scale assessed symptoms of depression and the Multidimensional Coping Inventory measured coping skills. The Autism Behavior Checklist provided a summary of their son or daughter’s behaviors that were difficult to manage.

Results were consistent with other research in demonstrating that maternal responses vary with the specific diagnosis of their child’s developmental disability. In general, mothers of individuals with fragile X syndrome had lower levels of psychological well-being than mothers of individuals with Down syndrome, but higher levels than mothers of individuals with autism. Group differences

depended somewhat on the particular measure of well-being, however. The behavior symptoms exhibited by affected children were the strongest and most consistent predictors of maternal well-being. Results also showed that there are many ways in which mothers used coping techniques to alleviate stress and reduce the effects of challenges in their lives.

The researchers recommended that parents of individuals with fragile X syndrome need to be provided social support and respite care to obtain relief from the stresses of challenging behaviors. They also suggested that interventions targeted at children as well as their parents would be helpful. Parents could benefit from programs designed to help them with their own needs and to manage the challenging periods of family life, such as transition times.



This research study is based on the following published article: Abbeduto L, Seltzer MM, Shattuck P, Krauss MW, Orsmond G, Murphy MM. Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal of Mental Retardation*. 2004; 109: 237-254. This summary was prepared by the Fragile X Research Registry. If you have any questions or would like to contact the researchers of this study, please send an e-mail to info@FragileXRegistry.org.