Conditions Associated with Fragile X Syndrome

Findings from the National Fragile X Survey

August 2009

This report provides information on nine conditions commonly associated with fragile X syndrome, including developmental delay, attention problems, hyperactivity, aggression, self-injurious behavior, autism, seizures, anxiety, and depression. Overall, males with the full mutation had the highest levels of reported conditions. Females with the full mutation also experienced these conditions, but to a lesser extent. These results highlight the need for clinicians and others who work with individuals who have fragile X syndrome to monitor the emergence of related conditions and provide treatment as early as possible.

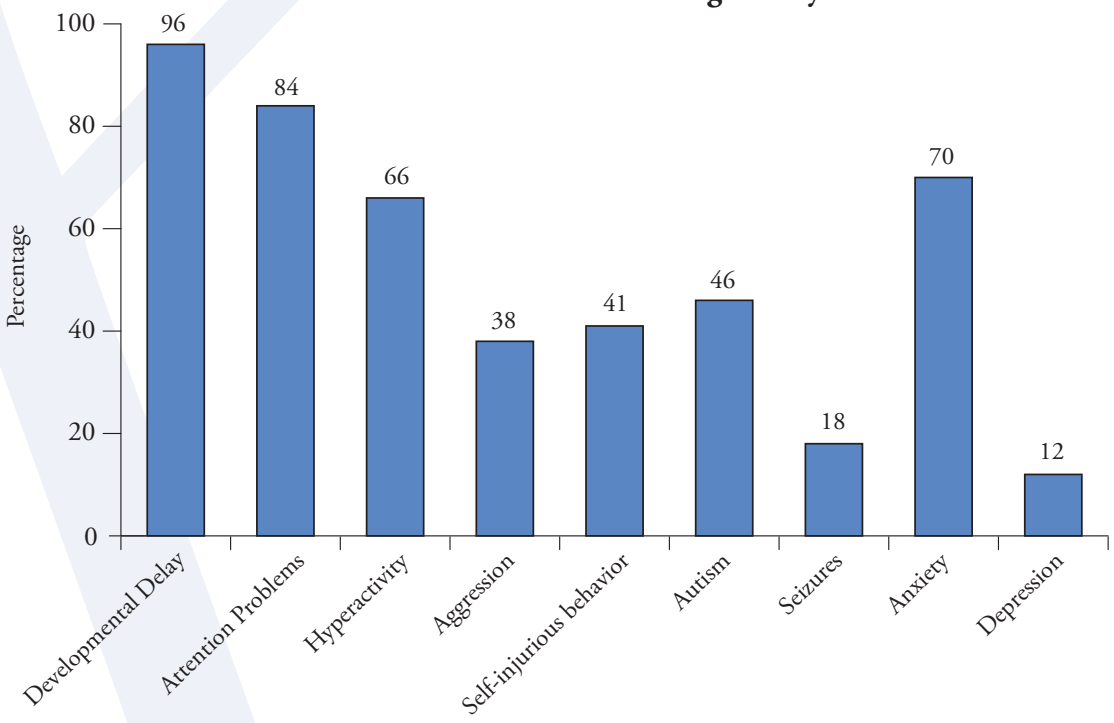
What other conditions are individuals with fragile X syndrome diagnosed or treated for?

Overview

This report provides information on nine conditions commonly associated with fragile X syndrome, including developmental delay, attention problems, hyperactivity, aggression, self-injurious behavior, autism, seizures, anxiety, and depression. Below, we present four charts which describe the percentages of individuals who have been treated or diagnosed with each condition. The charts are organized by males and females who have the full mutation of fragile X syndrome or are carriers. We limited the data to children and adults at least 6 years of age since many of the conditions would not be evident until then.

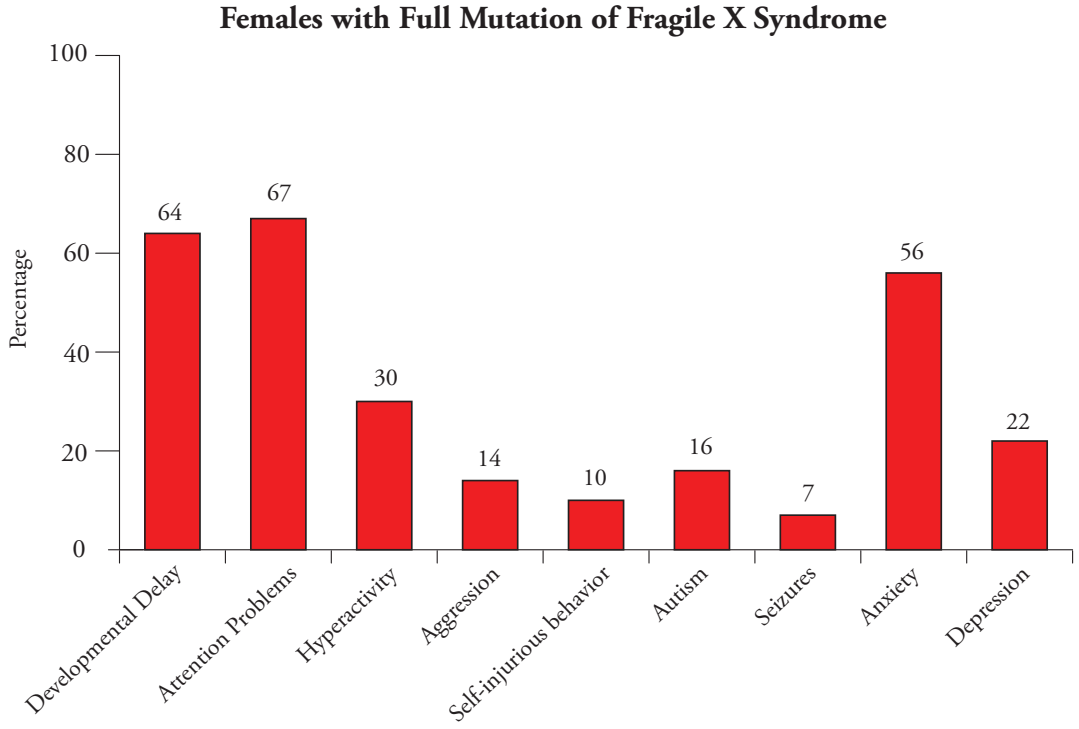
The first chart shows information for males with the full mutation. These percentages are based on data from 976 males, ages 6 to 62.

Males with the Full Mutation of Fragile X Syndrome



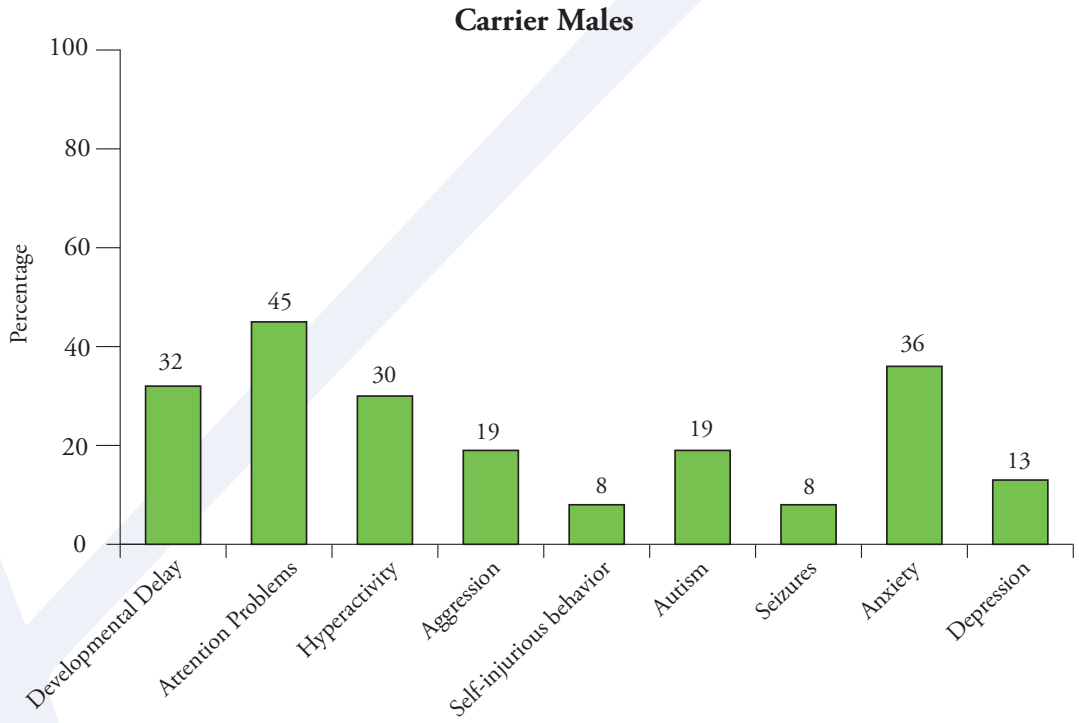
- Males with the full mutation experienced a wide range of other conditions.
- The most frequently reported conditions were:
  - ◊ Developmental delay (96%)
  - ◊ Attention problems (84%)
  - ◊ Anxiety (70%)
  - ◊ Hyperactivity (66%) and
  - ◊ Autism (46%)

The second chart shows information for females with the full mutation. These percentages are based on data from 259 females, ages 6 to 63.



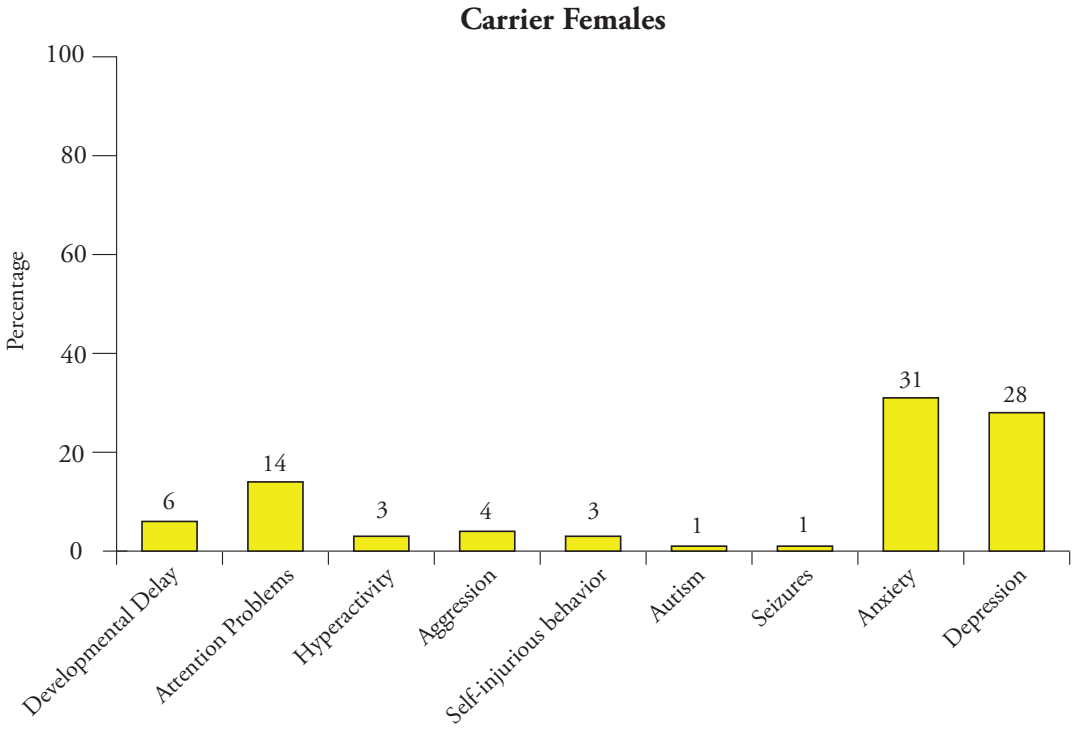
- The pattern for females with the full mutation was similar to that of males, but with fewer reported cases.
- The most frequently reported conditions were:
  - ◊ Attention problems (67%)
  - ◊ Developmental delay (64%)
  - ◊ Anxiety (56%)
  - ◊ Hyperactivity (30%) and
  - ◊ Depression (22%)

The next chart presents data for males who are carriers. These percentages are based on data from 57 males, ages 6 to 46.



- Families reported that carrier males had fewer reported conditions than either full mutation males or females.
- The most commonly reported conditions were:
  - ◊ Attention problems (45%)
  - ◊ Anxiety (36%)
  - ◊ Developmental delay (32%), and
  - ◊ Hyperactivity (30%)
- When compared to typically developing males the same age, carrier males were more likely to report developmental delay, attention problems, aggression, autism, seizures, and anxiety.

The last chart presents data for carrier females. These percentages are based on data from 199 females, ages 6 to 65.



- Similar to carrier males, carrier females displayed fewer associated conditions.
- The conditions most often reported were:
  - ◊ Anxiety (31%)
  - ◊ Depression (28%), and
  - ◊ Attention problems (14%).
- When compared to typically developing females the same age, carrier females were more likely to report developmental delay, attention problems, anxiety, and depression.

Summary of Results

Overall, we found that co-occurring conditions were frequently associated with fragile X syndrome but with different levels and patterns depending on gender and mutation status. Males with the full mutation had the highest levels of reported conditions. Females with the full mutation also experienced co-occurring conditions, but to a lesser extent. When compared to individuals without fragile X syndrome, carrier males and females were more likely to be diagnosed or treated for many conditions, such as attention problems and anxiety.

Acknowledgement

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For more information…

Please visit the National Fragile X Foundation web site at http://www.fragilex.org/html/fx_survey.htm

Suggested citation

Raspa, M., Bailey, D. B., & Bishop, E. (2008, August). Conditions associated with fragile X syndrome. Research Triangle Park, NC: RTI International. Available at https://fragileX.rti.org/USresults

These results also have been published in the American Journal of Medical Genetics, available at: http://www3.interscience.wiley.com/journal/117928899/grouphome/home.html

Reference: D. B. Bailey, M. Raspa, M. Olmsted, and D. Holiday (2008). Co-occurring conditions associated with *FMR1* gene variations: Findings from a national parent survey. *American Journal of Medical Genetics, 146A,* 2060-2069.

Questions?

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