Understanding the Daily Stress of Mothers of Adolescents and Adults with Fragile X Syndrome

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Introduction

Mothers of adolescents and adults with fragile X syndrome (FXS) are faced with unique challenges. The impact of these challenges on mothers’ daily lives and health is poorly understood. One goal of our longitudinal study is to understand the day-to-day experiences of mothers of adolescents and adults with FXS. Another goal is to understand how biological factors interact with stressful daily experiences to impact the psychological and physical well-being of mothers of adolescents and adults with FXS.

FXS is an X-linked disorder that is most commonly passed from mother to child. Mothers with the premutation of the FMR1 gene vary widely in terms of their affectedness. This is because, in part, some women have a high percentage of cells that have the normal X as the active X (as opposed to the premutation X) whereas other women have a low percentage of cells with the normal X as the active X (as opposed to the premutation X). The X activation ratio may serve as an important biological vulnerability factor, which alters the extent to which mothers with the premutation are negatively impacted by stressful daily experiences.

Individuals with FXS often exhibit behavior problems, including inattention, hyperactivity, aggression, and anxiety and autism symptoms. These behavior problems are an important source of stress for mothers. Mothers with low X activation ratio (i.e., more biochemically affected) may be particularly sensitive to, or negatively affected by, their son or daughter’s behavior problems.

Major Aims

1. To compare the daily experiences of mothers of adolescents and young adults with FXS to mothers of adolescents and adults without a disability.
2. To examine the extent to which mothers’ X activation ratio interacts with the experience of their child’s behavior problems to predict maternal cortisol levels, a physiological measure of stress.

Study Design & Participants

Our FXS study is an ongoing longitudinal study of 147 mothers of adolescents and adult children with FXS. The 131 mothers who had the premutation of the FMR1 gene and who completed the daily diary study are included in the present analyses. The daily diary involved telephone interviews on 8 consecutive days. Many mothers also provided saliva samples on 4 of these days, which allowed us to measure their cortisol.

Results

Major Aim 1

One-way ANCOVAs, controlling for maternal age and education, and child gender, were used to examine the daily experiences of mothers in the FXS sample and the comparison group of mothers. Results from these comparisons are shown in Figures 1 through 4.

Major Aim 2

In order to examine whether mothers’ X activation ratio serves as a biological vulnerability factor, we first examined the average daily cortisol levels for mothers with high (+mean) and low (-mean) X activation ratios.

Discussion

Our study highlights the day-to-day challenges of parenting an adolescent or adult with FXS. However, it also highlights that these mothers still find time for positive activities. Findings suggest that biological vulnerability factors (X activation ratio) interact with life stress to impact the psychological and physical health of mothers with the premutation. Mothers with low X activation ratio may be particularly sensitive to the negative impacts of their grown child’s behavior problems. We hope to share these and other findings with researchers and care providers to give new insights into the daily lives of mothers of adolescents and adults with FXS.

Acknowledgements

NICHD (P30 HD003100-S1); Graduate School, UW-Madison; Waisman center, UW-Madison (P30 HD03352).

Table 1. Participant Characteristics

<table>
<thead>
<tr>
<th></th>
<th>FXS (n=131)</th>
<th>Comparison (n=230)</th>
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</thead>
<tbody>
<tr>
<td>Maternal Characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some college + (%)</td>
<td>87%</td>
<td>68%</td>
</tr>
<tr>
<td>College</td>
<td>95%</td>
<td>91%</td>
</tr>
<tr>
<td>Married (%)</td>
<td>81%</td>
<td>75%</td>
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<td>Child characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (%)</td>
<td>82%</td>
<td>51%</td>
</tr>
<tr>
<td>Age (Mean [SD])</td>
<td>20.6 (7.1)</td>
<td>19.7 (11.3)</td>
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Figure 1. % of Days with Fatigue and Cutting Back at Work

Figure 2. % of Days with Stress at Home, Stress at Work, and Network Stress

Figure 3. Average Time (hours) spent in Physical Activity and Leisure

Figure 5. Daily Cortisol by X Activation Ratio

Figure 6. Daily Cortisol by X Activation Ratio and Behavior Problems

Figure 7. Cortisol Level by Internalizing Behavior Problems and X Activation Ratio (i.e., % of days with behavior problems).