Parenting Stress and Health in Mothers of Children with Intellectual Disability: A Williams Syndrome Advantage

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Introduction

Variation across different genetic disorders lead to unique behavioral phenotypes that often influence individual behavior. At the same time, different disorders show a high degree of similarity to one other. This “same and different” combination can inform us about indirect effects on the family—that is, do children’s behaviors influence parents to respond in certain ways? In particular, are maternal responses disability-specific or generalized across disabilities? Individuals with Autism Spectrum Disorders (ASD), Williams syndrome (WS), and Prader-Willi syndrome (PWS) have unique adaptive and maladaptive behaviors that are characteristic of their diagnosis and may challenge or be an advantage to their mothers.

Perceived maternal responses including psychological parenting stress, physical health status, depressive symptoms, and dispositional mindfulness have yet to be examined among families of offspring with ASD, WS, and PWS syndrome.

Objectives

The purpose of the present study was to compare the psychological stress, health, and mental health outcomes of mothers of children with ASD, WS, and PWS.
- How do mothers of children with ASD, WS, and PWS compare on self-reported parenting stress, depressive symptoms, health conditions, and dispositional mindfulness?
- How do children in the three groups compare on maternal reports of child behavior problems?
- How are child behavior problems correlated with parenting stress, depressive symptoms, and levels of dispositional mindfulness across diagnostic group?

Methods

Participants
Data included 306 mothers and their children with Williams syndrome (n = 107), Prader-Willi syndrome (n = 125), and Autism Spectrum Disorders (n = 124). There were 65 males and 9 females with ASD, 147 autistic disorder, 8 PDD-NOS, 19 Asperger’s, 55 males and 52 females with WS, and 68 males and 57 females with PWS. They ranged in age from 2 to 58 years with the following average ages: ASD (M = 8.90, SD = 5.60), WS (M = 17.34, SD = 10.85), PWS (M = 14.55, SD = 9.72).

Mothers ranged in age from 23 to 79 years with the following average ages in each group: ASD (M = 36.84, SD = 6.41), WS (M = 47.93, SD = 10.58), and PWS (M = 46.65, SD = 9.84). Overall, mothers were well-educated—25.8% completed a graduate or professional degree, 33.6% had a 4-year degree, 16.1% had a 2-year degree, and 19.1% had a high school degree. The majority of mothers were white (85.6%), 4.6% were African-American, and 5.6% reported an ‘other’ race.

Seventy-eight percent of mothers were married to the child’s father, 18.7% were not, and another 3.7% of mothers were separated. Our sample was fairly advantaged with 34.5% earning more than $100,000 in annual household income. Percentage of families that fell within other annual household incomes was: less than $15,000 (3.1%), $15-29,000 (7.3%), $30-49,900 (13%), $50-69,000 (18.2%), $70-99,000 (23.4%), and over $100,000 (34.3%). Mothers who were employed outside of the home worked an average of 19.84 hours (ASD), 25.15 hours (WS), and 17.30 (PWS).

Parent Measures
- Demographics questionnaire
- A general Health questionnaire
- Parenting Stress Index (PSI-short form)
- Beck Depression Inventory (BDI)
- Day to Day Experiences (DDE: mindfulness)

Procedure
This study was part of a longitudinal study examining child and family well-being in children with genetic and intellectual and developmental disabilities (IDD). It investigated the developmental, psychological, and health outcomes of children with IDD and their families.

Children and families were recruited from across the country to learn more about their specific disability as well as the health and well-being of their families.

Consenting mothers completed a battery of assessments while their children were assessed in clinic. Only the maternal self-report data were analyzed for the purposes of this study.

Results

- Child age, mother age, and annual household income differed by group and were covaried in each of the following analyses:
- There were significant differences for stress scores on the PSI by group (F(2,233)=5.96, p<.001).
- Pairwise comparisons indicated that:
  - WS mothers (M=27.61) reported significantly lower Parental Distress than ASD mothers (M=34.16).
  - WS mothers (M=23.85) reported significantly less Parent-Child Dysfunctional interaction than ASD (M=28.93) and PWS (M=29.05) mothers.
  - WS mothers (M=32.85) reported significantly lower scores on the Difficult Child subscale as compared to ASD mothers (M=39.83), and ASD mothers had higher scores than PWS mothers (M=34.71).
  - WS mothers (M=84.31) had lower Total Stress compared to ASD (M=102.91) and PWS (M=93.54) mothers. See Figure 1.
- When using a cut-off to establish clinically significant levels of perceived stress, the groups were significantly different from each other (χ²(2)=22.53, p<.001).
- The proportion of mothers of children with WS who experienced clinical levels of psychological stress was significantly lower compared to mothers of children with ASD (χ²(2)=22.04, p<.001) and PWS (χ²(2)=8.10, p=.004) See Table 1.
- There were significant group differences for child behavior problems (F(2,233)=3.86, p<.001). Children with WS scored lower (M = 12.93) than children with ASD (M = 25.49) and PWS (M = 21.49) on overall behavior problems, p<.01.
- For the ASD group child behavior problems were positively correlated with stress. For the ASD and PWS groups, total child problems and internalizing problems (e.g., anxiety) were positively correlated with maternal depressive symptoms.

Conclusions

- Mothers of children with WS experienced less stress than mothers of children with ASD or PWS.
- This may be accounted for by the positive traits that individuals with WS possess, but also by maladaptive behavior problems common in ASD and PWS.
- Adverse health effects for caregivers of children with health problems and neurological disorders have been documented and recent research indicates this may hold for parents of children with intellectual disabilities as well (Miodrag & Hodapp, 2010; 2011).
- While no associations with physical health were found, the percentages of mothers experiencing clinically significant levels of stress indicates they may be at risk for adverse physical health outcomes.

- Mindfulness-based practice has been shown to reduce stress and increase coping in clinical populations and the links between mindfulness and maternal well-being warrants further study in the context of families of children with disabilities.

- Limitations and Future Directions
- The health measure used was relatively limited, potentially contributing to the lack of findings.
- Sample size limited our ability to identify effects by maternal age group.
- Lack of a control group. Are WS mothers still stressed compared to the general population?

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Table 1. Percent of sample experiencing clinically significant stress levels by diagnostic group

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>% experiencing clinically significant stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td>70.3%</td>
</tr>
<tr>
<td>PWS</td>
<td>53.0%</td>
</tr>
<tr>
<td>WS</td>
<td>34.0%</td>
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</tbody>
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Results Cont’d