Parent Stress Prior To An Autism Spectrum Disorder Diagnostic Evaluation: A DBPNet Study

Yair Voliovitch, MD
Fellow, Developmental and Behavioral Pediatrics, Yale School of Medicine, Connecticut

Abstract co-authors:
Carol Weitzman, Abha R. Gupta, John M. Leventhal, Ada Fenick, Marilyn Augustyn, Sarabeth Broder-Fingert, Emily Feinberg, Nathan Blum, Veronika Shabanova
Disclosures

Funded by:
• National Institute of Mental Health # R01MH104355.

• No conflicts of interest.
Autism and Parental Stress

• Parental stress is high in parents with children with ASD, even compared with parents of children with other developmental delays.

• Post-diagnostic parental stress is associated with:
  1. Impaired parenting skills
  2. Impaired family functioning & decreased family quality of life
  3. Disturbances in marital relationships
  4. Difficulties with child behavior

• Higher levels of social support, after the diagnosis of ASD, moderate parental stress.
What We Do Not Know

- Studies of stress in parents of children with ASD have been examined after diagnosis.
- No study to date, however, has examined the stress parents are experiencing prior to diagnosis.
Purpose

To examine:

1. The relationships prior to diagnostic evaluation between:
   – parent-rated ASD symptoms and adaptive functioning in their child and
   – parental stress

2. Whether social support moderates these relationships
Hypothesis

ASD Symptoms

Social support

Adaptive functioning

PARENTAL STRESS

+ 

-
Overview – Project EARLY

• Multisite, randomized controlled trial.
• To test the effectiveness of a family navigator in reducing time to diagnosis and increasing access to treatment services in underserved, primarily minority children at risk of ASD, compared with care coordination only.
• 3 primary sites:
  – Boston Medical Center (6 pediatric primary care clinics)
  – Yale New Haven Hospital (2 pediatric primary care clinics)
  – Children’s Hospital of Philadelphia (2 pediatric primary care clinics)
• This study focused on baseline data
Inclusion criteria

• Children aged 15-27 months
• Screened positive for ASD at a primary care visit, or parent or clinician-identified concerns.
• No previous diagnosis of ASD
Measures

Modified Checklist for Autism in Toddlers/Revised

Social support

Adaptive functioning

Parental stress

+ 

-
Modified Checklist for Autism in Toddlers/Revised: MCHAT-R

- Screening tool for autism with 20 questions.
- Score lower than 3 → no need of follow up
- Score equal or greater than 3 → administer MCHAT-R follow up interview and if score is greater than 2, represents a medium risk
- Score greater than 7 represents a high-risk for autism
Measures

- Modified Checklist for Autism in Toddlers/Revised
- Social support
- Adaptive Behavior Assessment System

Parental stress

+ 
-
Adaptive Behavior Assessment System: ABAS-3

• Three subscales:
  1. Self-direction
  2. Social
  3. Communication
• Score lower than 7 considered below average.
• Score lower than 5 considered low.
Measures

- Modified Checklist for Autism in Toddlers/Revised
- Medical Outcome Study Social Support Survey
- Adaptive Behavior Assessment System

Parental stress
Medical Outcome Study Social Support Survey: MO-SSSS

• Comprised of 19 questions.
• Scored on a 1-5 scale, where 5 represents the greatest feeling of support.
Measures

- Parental stress
  - Parenting Stress Index – short form (PSI-SF)
    - Total stress score
    - Difficult child subscale
    - Parent-child dysfunctional interaction subscale

- Adaptive Behavior Assessment System
- Medical Outcome Study Social Support Survey
- Modified Checklist for Autism in Toddlers/Revised
Parental Stress Index- Short Form (PSI-SF)

• Total score and 2 subscales:
  1. Difficult child subscale
  2. Parent-child dysfunctional interaction subscale

• Stress is considered clinically significant for a score greater than the 85th percentile.
Covariates

• Demographics
  – Child age and gender
  – Parental age
  – Race
  – Ethnicity
  – Insurance status
  – Born in the United States
  – Marital status
  – Parental education

• Family resources
  - Enrollment in EI
  - WIC nutrition program
  - Food stamps
  - Subsidized housing
  - Cash assistance

• Psychosocial stressors
  - Domestic violence
  - Substance use
Data analysis – 1st hypothesis

To examine the relationship between parent-rated ASD symptoms and adaptive functioning in their child and parental stress:

1. Calculated unadjusted associations between the MCHAT and ABAS scores with PSI-SF, using Pearson correlation (r)

2. Adjusted Associations by:
   - Adding variables from the unadjusted associations at p<0.10 to the model.
   - Performing multivariable linear regression, using stepwise selection with p=0.15 for entry and remaining in the model.
Data analysis – 2\textsuperscript{nd} hypothesis

To examine whether social support moderates these relationships:

1. We used the Interaction terms between social support and MCHAT-R, as well as social support and ABAS subscales in the same model, to assess effect modification.
# Results

## Baseline characteristics (N=317)

<table>
<thead>
<tr>
<th>Child demographics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>70%</td>
</tr>
<tr>
<td>Child age, mean (SD)</td>
<td>21.8 months (3.45)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent demographics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent age, mean (SD)</td>
<td>31.8 years (7.3)</td>
</tr>
<tr>
<td>Black/African-American</td>
<td>57%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>28%</td>
</tr>
<tr>
<td>Public insurance</td>
<td>82%</td>
</tr>
<tr>
<td>Born in the United States</td>
<td>62%</td>
</tr>
<tr>
<td>Married</td>
<td>55%</td>
</tr>
<tr>
<td>High school/GED or higher</td>
<td>82%</td>
</tr>
</tbody>
</table>
## Results
### Family Resources and Psychosocial Stressors

<table>
<thead>
<tr>
<th>Variable</th>
<th>Percent reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receiving EI</td>
<td>46%</td>
</tr>
<tr>
<td>Receiving WIC nutrition program</td>
<td>67%</td>
</tr>
<tr>
<td>Receiving food stamps</td>
<td>62%</td>
</tr>
<tr>
<td>Receiving subsidized housing</td>
<td>20%</td>
</tr>
<tr>
<td>Receiving cash assistance</td>
<td>22%</td>
</tr>
<tr>
<td>Domestic/sexual assault support</td>
<td>3%</td>
</tr>
<tr>
<td>Reported substance abuse</td>
<td>4%</td>
</tr>
</tbody>
</table>
## Results
### Key variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MCHAT-R score</strong></td>
<td>8.6 (3.0)</td>
</tr>
<tr>
<td><strong>ABAS</strong></td>
<td></td>
</tr>
<tr>
<td>• Communication</td>
<td>4.7 (2.4)</td>
</tr>
<tr>
<td>• Social</td>
<td>5.2 (2.5)</td>
</tr>
<tr>
<td>• Self-direction</td>
<td>5.2 (3.0)</td>
</tr>
<tr>
<td><strong>MO-SSSS</strong></td>
<td>3.8 (1.0)</td>
</tr>
<tr>
<td><strong>PSI-SF</strong></td>
<td></td>
</tr>
<tr>
<td>• Total stress</td>
<td>88.6 (25.4)</td>
</tr>
<tr>
<td>• Parent/child dysfunction</td>
<td>27.7 (8.4)</td>
</tr>
<tr>
<td>• Difficult child</td>
<td>31.3 (10.5)</td>
</tr>
</tbody>
</table>
## Hypothesis 1

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unadjusted(^1)</th>
<th>Adjusted Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCHAT-R score</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ABAS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Self-Direction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Social</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Communication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MO-SSSS</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^1\)Pearson correlation for continuous predictor

*\(p<0.05\), **\(p<0.01\), ***\(p<0.001\)
Hypothesis 2

• Social support did not moderate the association between parent-rated ASD symptoms and adaptive functioning and parental stress.
Conclusions

First hypothesis
• After adjusting for multiple variables, parent-rated ASD symptoms were shown to have a positive association with parental stress level before a diagnostic evaluation was completed.
• Only one subscale of the adaptive function measure, the self-direction subscale, had a negative association with parental stress.

Second hypothesis
• While higher social support negatively correlates with parental stress, it does not moderate the effect of symptoms or adaptive functioning on parental stress.
Clinical implications

- Our study is the first to assess parental stress before an evaluation is completed in children at risk for ASD.
- This study provides a glimpse into the parental minds at this critical time, and offer us data regarding the various variables that can affect parental stress in this period.
- The importance of social support is yet again demonstrated as an essential instrument to alleviate parental stress.
- Due to the well-studied effect of stress on family-life in general and child development specifically, clinicians may consider assessing for stress in parents of children at risk of ASD even before they have been evaluated.
ACKNOWLEDGMENT

- Project EARLY teams at:
  - Yale New-Haven Hospital
  - Boston Medical Center
  - Children’s Hospital Of Philadelphia

- DBPnet

- National Institute Of Mental Health

- All the families who participated in the study

Yale New-Haven team:
- Carol Weitzman
- Ada Fenick
- John M. Leventhal
- Abha R. Gupta
- Veronika Shabanova
- Marisol Credle
- Jenny Acevedo
- Cynthia Guillen
<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
<th>Mean (SD)</th>
<th>Total Stress Score</th>
<th>Parent-Child Dysfunction Subscale</th>
<th>Difficult Child Subscale</th>
<th>Total Stress Score F-Value</th>
<th>Parent-Child Dysfunction Subscale F-value</th>
<th>Difficult Child Subscale F-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCHAT score</td>
<td>317</td>
<td>8.65 (3.0)</td>
<td>0.14*</td>
<td>0.17**</td>
<td>0.19***</td>
<td>6.25**</td>
<td>5.20*</td>
<td>3.83*</td>
</tr>
<tr>
<td>ABAS Self-Direction Scale Score</td>
<td>315</td>
<td>5.21 (3.0)</td>
<td>-0.19***</td>
<td>-0.16**</td>
<td>-0.23***</td>
<td>4.35*</td>
<td>8.81***</td>
<td></td>
</tr>
<tr>
<td>ABAS Social Scale Score</td>
<td>312</td>
<td>5.23 (2.6)</td>
<td>-0.11*</td>
<td>-0.13*</td>
<td>-0.14*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ABAS Communication Score</td>
<td>312</td>
<td>4.70 (2.4)</td>
<td>-0.06</td>
<td>-0.08</td>
<td>-0.07</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td>314</td>
<td>3.77 (0.97)</td>
<td>-0.38***</td>
<td>-0.32***</td>
<td>-0.25***</td>
<td>43.53***</td>
<td>33.53***</td>
<td>20.26***</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or living with partner</td>
<td>174 (55.1)</td>
<td>84.9 (24.5)</td>
<td>26.7 (8.1)</td>
<td>30.0 (9.8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/Separated/Divorced</td>
<td>142 (44.9)</td>
<td>92.9 (26.1)</td>
<td>28.8 (8.7) *</td>
<td>32.8 (10.1) **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent born in US</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>197 (62.1)</td>
<td>90.0 (26.2)</td>
<td>27.8 (8.8)</td>
<td>32.6 (10.6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>120 (37.9)</td>
<td>86.1 (23.9)</td>
<td>27.4 (7.8)</td>
<td>29.3 (8.8) **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receipt of cash Assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>69 (21.8)</td>
<td>98.9 (26.2)</td>
<td>30.4 (8.5)</td>
<td>35.8 (10.6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>248 (78.2)</td>
<td>85.7 (24.5)</td>
<td>26.9 (8.3) **</td>
<td>30.1 (9.5) ***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receipt of food stamps</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>196 (61.8)</td>
<td>91.1 (25.2)</td>
<td>28.3 (8.5)</td>
<td>32.6 (10.3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>121 (38.2)</td>
<td>84.4 (25.3)</td>
<td>26.7 (8.3)</td>
<td>29.3 (9.3) **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Pearson Correlation for Continuous Predictor, Means (Standard Deviation) for Categorical Predictors

*p<0.05, **p<0.01, *** p<0.001