Stress and Health in Caregivers of Children with Autism Spectrum Disorders

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Stress & Health
- Consists of stressors, mediators and the stress response
- Adaptive in the face of dangers
  - BUT
    - Prolonged stress can be damaging
      - Especially if stressors are psychological

ASD & Stress
- ASD found to give rise to one of the most complex networks of family stressors
- Parents found to have higher stress levels than:
  - General population
  - Parents of children with other developmental disorders, e.g., developmental delay, Down syndrome, cerebral palsy

Previous research
- Some associated factors have been identified:
  - Severity of ASD symptoms (Hastings & Johnson, 2001)
  - Behaviour problems (Eisenhower et al., 2005)
  - Sleep problems (Polimeni, 2005)
  - BUT...
    - Some discrepancy in the literature
    - Majority focus only on self-reports

Ambulatory Blood Pressure Monitoring
- Link between stress & disease may take time to emerge
- Portable BP monitor worn in the natural environment
- Enables repeated observations of BP & HR under natural conditions
- Night-time dip
Salivary biomarkers

- Activation of the HPA axis ⇒ Hormone cortisol
- Activation of the sympathetic nervous system ⇒ Enzyme alpha amylase (sAA)

Present Research

- Three inter-related studies:
  - Study 1: 80 mothers of children with ASD
  - Study 2: 20 mother-father pairs of children with ASD
  - Study 3: Matched control group of 20 mother-father pairs of typically developing children

Procedure

- 1 day, natural environment, normal daily routine
- ABP monitoring:
  - Worn for 24 hours
  - Recorded systolic (SBP) & diastolic (DBP) blood pressure & heart rate (HR)
  - 20 minute intervals (day)
  - 45 minute intervals (night)

Procedure

- Cuff inflation diary:
  - Location
  - Caregiving
  - Social interactions
  - Work duties
  - Mood

Procedure

- Saliva samples collected using Salimetrics Oral Swabs
- Morning:
  - Immediately, 15, 30 & 45 mins after waking (CAR)
- Afternoon:
  - 12pm, 4.30pm & 9pm
  - Alpha-amylose (sAA)

Procedure

- Questionnaires (Participant)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Scale</th>
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</thead>
<tbody>
<tr>
<td>Parenting stress</td>
<td>Parenting Stress Index: Short Form (PSI)</td>
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<tr>
<td>Anxiety &amp; depressive symptoms</td>
<td>Hospital Anxiety &amp; Depression Scale (HADS)</td>
</tr>
<tr>
<td>Coping strategies</td>
<td>Brief COPE</td>
</tr>
<tr>
<td>Social support</td>
<td>Short Form Social Support Questionnaire (SSQ-6)</td>
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<tr>
<td>Sleep quality</td>
<td>Pittsburgh Sleep Quality Index (PSQI)</td>
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<tr>
<td>Level of caregiving responsibility</td>
<td>Parental Responsibility Scale (PRS)</td>
</tr>
<tr>
<td>Personal &amp; demographic info</td>
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</tr>
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</table>
Procedure

- Questionnaires (Child)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Scale</th>
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<tbody>
<tr>
<td>ASD severity</td>
<td>Gilliam Autism Rating Scale (GARS)</td>
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<tr>
<td>Adaptive skills</td>
<td>Vineland Adaptive Behaviour Scales (VABS)</td>
</tr>
<tr>
<td>Child behaviour problems</td>
<td>Behaviour Problems Inventory (BPI)</td>
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<td>Child sleep habits</td>
<td>Child’s Sleep Habits Questionnaire (CSHQ)</td>
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<tr>
<td>ADHD symptoms</td>
<td>Conners’ Parent Rating Scale (CPRS)</td>
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<tr>
<td>Child &amp; family information</td>
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</tr>
</tbody>
</table>

Present Research

- Three inter-related studies:
  - Study 1: 80 mothers of children with ASD
  - Study 2: 20 mothers & 20 fathers of children with ASD
  - Study 3: Matched control group of 20 mothers & 20 fathers of typically developing children

Participants

<table>
<thead>
<tr>
<th>Participant Age (years)</th>
<th>Mean</th>
<th>Min</th>
<th>Max</th>
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<tbody>
<tr>
<td>Number of children with a diagnosis</td>
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<td>41</td>
<td>65</td>
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<tr>
<td>Quantity illnesses (current)</td>
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<td>9</td>
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<td>Child Age (year:month)</td>
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<tr>
<td>Child Gender</td>
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<td>Male</td>
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<tr>
<td>Female</td>
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<td>ASD Diagnosis</td>
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<tr>
<td>Autism</td>
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<td>Asperger’s syndrome</td>
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<tr>
<td>Quantity of Diagnoses</td>
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</tbody>
</table>

Results

- Preliminary results
- Relationship of child & parent characteristics to:
  - Self-reported stress, anxiety & depression symptoms
  - Cardiovascular (CV) measures (SBP, DBP, HR)
  - Salivary biomarkers:
    - Cortisol peak
    - Alpha-amylase

Behaviour Problems

- Self-reported stress, anxiety and depression:
  - Higher Self-injury Frequency & Severity associated with higher ‘Difficult Child’
  - Higher Stereotypy and Aggression Frequency & Severity associated with higher Anxiety, Parenting Stress, Difficult Child and Parent-Child Dysfunctional Interaction.

- Cardiovascular:
  - Higher frequency of behaviour problems the day before blood pressure monitoring associated with higher awake SBP and asleep HR.

- Cortisol / Alpha-Amylase:

ADHD Symptoms

- Self-reported stress, anxiety and depression:
  - Higher Oppositional Behaviour, Inattention and ADHD symptoms associated with higher Anxiety, Depression and Parenting Stress
  - Higher Hyperactivity associated with higher Parenting Stress.

- Cardiovascular:
  - N/A

- Cortisol / Alpha Amylase:
  - N/A
**Child Sleep Problems**

- Self-reported stress, anxiety and depression:
  - Higher Child Sleep Dysfunction, Daytime Sleepiness, Bedtime Resistance and Sleep Duration associated with higher Parenting Stress and Parent-Child Dysfunctional Interaction.
  - Higher Parasomnias associated with higher Anxiety and Depression.

- Cardiovascular:
  - Higher Bedtime Resistance associated with higher asleep HR.
  - Higher Night Wakeings associated with smaller SBP night-time dip.

- Cortisol / Alpha Amylase:
  - Higher Child Sleep Dysfunction, Night Wakeings & Sleep Onset Delay associated with smaller cortisol awakening response.

**Social Support & Coping Strategies**

- Higher quantity of social supports associated with less Depression symptoms.
- Use of Behavioural Disengagement associated with increased Anxiety, Depression, Stress and 24 hr SBP and DBP.
- Use of Emotional Support associated with less Depression and lower DBP.
- Use of Positive reframing associated with lower SBP & DBP.

**Parent Sleep**

- Self-reported stress, anxiety and depression:
  - Higher Sleep Dysfunction associated with higher Anxiety, Depression symptoms and Parenting Stress.
  - Higher Anxiety, Depression and Parenting Stress also associated with subscales: Sleep Quality, Latency, Duration, Efficiency, Disturbances and Daytime Dysfunction.

- Cardiovascular:
  - Higher Sleep Dysfunction associated with higher SBP and DBP and lower SBP dip.
  - CV measures also positively correlated with a number of subscales: Sleep Quality, Duration, Efficiency, Disturbances and Daytime Dysfunction.

- Cortisol / Alpha Amylase:
  - Higher Sleep Disturbances and Daytime Dysfunction associated with higher CAR.

**Unmet Needs**

- Self-reported stress, anxiety and depression:
  - More Unmet Service Needs associated with higher Depression symptoms, Parenting Stress, Parent-Child Dysfunctional Interaction and Parental Distress.

- Cardiovascular:
  - Higher unmet services and supports associated with higher 24 hour SBP.

- Cortisol / Alpha Amylase:
  - More unmet services associated with higher cortisol awakening response.

**Policy/Services implications**

- Unmet service needs
  - Demonstrates the importance of adequate & appropriate service provision for the wellbeing of the parents as well as the child

- Sleep
  - Respite
  - Interventions and support around sleeping issues

**Implications for supporting parents**

- Consider supports in place for parents
  - Support in managing child’s behaviour
  - Support in caring for the child if needed
  - Emotional support

- Importance of parents taking care of themselves

- Consider different supports needed for mothers and fathers
Future directions

- Identify factors that best predict stress
- Factors associated with positive outcomes
- Differences between mothers and fathers
- Physical markers of stress
  - Explore dysregulation of CAR

Thank you to all the parents who took part in this research.