Psychosocial and Biological Markers of Stress in Mothers of Adolescents and Adults with ASD

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Images of Autism in the Media

- Almost exclusively focused on early childhood.
- Children are portrayed alone, not in a family context.
Autistic and Seeking a Place in an Adult World
An Artist's Struggle for Independence as He Leaves School Behind

By JEFF GILLARD

MCNULTY, N.Y. — For weeks, Justin Caffrey, a high school senior, has been working on a portfolio of his comic strips and a gift for sharing. It’s part of his final project at the school, and it’s a reflection of his struggle to find a place in an adult world.

Justin, who suffers from autism, has been working on a portfolio of his comic strips and a gift for sharing. It’s part of his final project at the school, and it’s a reflection of his struggle to find a place in an adult world.

Justin, who has autism, has been working on a portfolio of his comic strips and a gift for sharing. It’s part of his final project at the school, and it’s a reflection of his struggle to find a place in an adult world.
Our Research

- Prospective, longitudinal study spanning 12 years in the life of each family (1998-2012).

- Repeated measures of the mother, father, siblings, and adolescent/adult with ASD.

- Overall goal: to investigate the course of change in the behavioral phenotype of autism during adolescence and adulthood, and its impact on the family.
Diagnostic Boom

- 1990: beginning of the surge in diagnosis of autism
- Children diagnosed in the 1990s are currently exiting HS
- Increasing focus on adulthood


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NIH Inter-Agency Coordinating Council on Autism (1/19/10)

- Question 6: What does the future hold, particularly for adults?
  - Need for studies of the scope and impact of the spectrum of autism in adults, including critical life transitions.
  - Need for longitudinal studies that follow carefully characterized cohorts and their families into adulthood to understand the risk and protective factors that account for quality of life outcomes.
Limitations of Past Research

- Small samples, underpowered to detect change
- Primarily recruited from clinic populations
- Few studies extend beyond early adolescence
- Few studies focused on the family
One other fact stands out prominently. In the whole group, there are very few really warmhearted fathers and mothers. For the most part, the parents, grandparents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in people. Even some of the happiest marriages are rather cold and formal affairs. Three of the marriages were dismal failures. The question arises whether or to what extent this fact has contributed to the condition of the children.
Our Research Design

- Large sample (n=406)
- Recruited from the community
- Wide age range -- 10 to 52 years of age at Time 1 (1998)
  - 62% adolescents age 10-21
  - 38% adults age 22-52
Study Timeline

12 Years

Time 1
Time 2
Time 3
Time 4
Time 5 Daily Diary/Cortisol
Time 6
Time 7
Time 8

18 Months

Daily Diary Cortisol
Broad Focus of our Research

- Change in autism symptoms and behavior problems during adolescence and adulthood.
- Changes associated with the transition out of high school.
- Reciprocal relationship between the well-being of the person with ASD and the well-being of the mother.
- Impacts on siblings.
- Impacts on the marital relationship.
- Family resilience.

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Research Question for Today

- How do mothers of adults with ASD differ from the general population in daily stress and cortisol levels?
Why Focus on Mothers and their Stress?

- Mothers are the primary caregivers in most (but not all) families in our research.
- A focus on stress is just one perspective, and it doesn’t outweigh the importance of research on resilience.
Time 1 Sample Characteristics

- mean age:
  - 22 years (individual with autism)
  - 51 years (mother)
- 73% male
- 65% living with parent(s) at Time 1
- 74% verbal (use of 3+ word phrases)
- 95% had Autistic Disorder
- mean household income: $52,600
Co-morbidity

- Intellectual Disability 70%
- Seizures 22%

- Any mental health dx 51%
  - anxiety disorder 29%
  - OCD 25%
  - depression 18%
  - ADHD 16%
  - schizophrenia 1%
  - bipolar disorder 6%
Prescription Medications

- 75.3% take at least 1 prescription medication
- 15 take 5 different medications
- Mean # (of those taking medications) = 2.75
- anti-convulsants 38% (of full sample)
- anti-depressants 35%
- anti-psychotics 25%
- anti-anxiety 18%
Time 5 Daily Diary Study

- 8 days, 15 min telephone calls every evening, assessment of mother’s time use, daily stresses, positive events, mood, physical health.

- On days 2 – 5, mothers collected 4 saliva samples each day (when they wake up, 30 minutes later, at lunch, at bedtime).

- Comparison group of mothers matched on mothers’ education, income, marital status, having a child living at home, but no child with disabilities, drawn from a nationally representative sample (MIDUS).
Mothers’ Daily Time Use

![Bar chart showing mothers' daily time use](chart.png)

- **Sleeping**: Autism group significantly higher than the comparison group.
- **Childcare**: Comparison group significantly higher than the Autism group.
- **Chores**: Comparison group is significantly higher than the Autism group.
- **Work**: Comparison group significantly higher than the Autism group.
- **Leisure**: Autism group significantly higher than the comparison group.
- **Watching TV**: Comparison group significantly higher than the Autism group.
- **Physical Activity**: Comparison group significantly higher than the Autism group.

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**Note:** The chart indicates the number of hours spent on various activities by mothers with autistic children and a comparison group. The stars (*) indicate significant differences between the two groups.
Percent of Diary Days with Fatigue and Interference with Work

![Bar chart showing the percent of days with fatigue and interference with work for Autism and Comparison groups.](chart_image)
Maternal Daily Stress

- Arguments
- Avoided Arguments
- Work Stress
- Home Stress
- Network Stress

Percent of Days

* Autism
* Comparison
Maternal Daily Emotional Support

![Bar chart showing percent of days with emotional support given and received for Autism and Comparison groups. The chart indicates a significant difference (*) in the number of days with emotional support given and received between the two groups.](chart.png)

- **Gave Emotional Support**
  - Autism: [Bar Height]
  - Comparison: [Bar Height]

- **Received Emotional Support**
  - Autism: [Bar Height]
  - Comparison: [Bar Height]
Daily Behavior Problems: Acute Stress During Diary Study

- Repetitive Behavior
- Withdrawn
- Uncooperative
- Socially Offensive
- Hurtful to Property
- Hurtful to Others
- Hurtful to Self
- Any Behavior Problem

Percent of Children
Daily Life of Mothers of Adults with Autism

- Less positive affect, more negative affect
- More fatigue
- More intrusions in their work day
- More time spent in childcare, chores
- Less time spent on leisure
- More stress of all types
- Greater exchange of emotional support
- Exposure to high levels of behavior problems
Daily Life of Mothers of Adults with Autism

- High level of intensity.

- What are the consequences of this level of intensity for the mother’s health, across many years and decades?
Physiological Effects of Daily Stress

- Cortisol measured 4x/day for 4 days as part of the Daily Diary Study (Days 2 - 5).

- Saliva is collected on “salivettes” and analyzed for cortisol.

- Assayed in Kirschbaum lab (Dresden)
Cortisol

- End product of the hypothalamic-pituitary-adrenal (HPA) axis.
- A hormonal marker of stress.
- Implicated in psychiatric and somatic disorders (e.g., Bhattacharyya, Molloy, & Steptoe 2008; McEwen et al. 1997).
- Important for glucose production, fat metabolism, and inflammatory responses (e.g., Heim, Ehlert, & Hellhammer, 2000).
Normal Pattern of Cortisol Expression

- cortisol (nmol/L)
- time of day: wake, out of bed, lunch, go to bed
- graph showing cortisol levels varying throughout the day
Dysregulation of Cortisol

- Acute stress – hyperactivation
- Chronic stress – hypoactivation
  - Parents of children with cancer
  - PTSD

![Graph showing the diurnal rhythm of cortisol](graph.png)
Which Pattern of Cortisol in Mothers of Adults with ASD?

- Hyperactivation, reflecting acute daily stress?
- A normative pattern?
- Hypoactivation, reflecting the chronic stress of parenting?
Cortisol Expression by Groups

Comparison

Autism

Wake
Out of Bed
Lunch
Go to bed

time of collection

Cortisol level (nmol/L)
Hypoactivation

- Reflective of the toll taken by chronic stress and the fatigue observed in the Diary Study.

- In follow-up studies, we identified three factors that predict hypoactivation of cortisol:
  - behavior problems
  - daily stress
  - life events
Conclusions

- Physiological toll (low cortisol) of long-term parenting.
- Other data show elevated rates of health problems and functional limitations by ~ age 60 in mothers and fathers of adults with DDs.
- Lifetime cost of ASD (estimated at $2.6M) -- ignores the impact on the family in lost time at work, psychosocial stress, and illness.
- Need for continued services in adulthood and family support.
Acknowledgements

Lifespan Family Research Laboratory - www.waisman.wisc.edu/family/

- Jan S. Greenberg, PhD, Co-PI
- Leann Smith, PhD
- Jinkuk Hong, PhD
- Renee Makuch
- Julie Lounds Taylor, PhD (now at Vanderbilt Kennedy Center)
- Sigan Hartley, PhD (now at UW-Madison)
- Gael Orsmond, PhD (now at Boston University)
- Paul Shattuck, PhD (now at Washington University in St. Louis)
- Erin Barker, PhD (now at Concordia University in Montreal)

Marty Wyngaarden Krauss, PhD – Brandeis University
David Almeida, PhD – Penn State University
Chris Coe, PhD – UW-Madison

Funding: NIA (R01 AG08768), NICHD (P30 HD03352, T32 HD07489)
- Nancy Lurie Marks Family Foundation