An Unanticipated Life: The Impact of Lifelong Caregiving

Marsha Mailick Seltzer, PhD
Research on Developmental Disabilities

- **Cause** – genetic, environmental, both

- **Consequences** - physical, social, psychological (for the child and for the family)

- **Cures and treatments** - medication, early intervention
Topics for Today

- The daily life of families of adolescents and adults with autism and how it differs from the norm.

- How the family environment can affect the symptoms of the individual with autism.
What is Autism?

- A developmental disability beginning before age 3, with impairments in communication, social interaction, and behavior.
Autism Continues Across the Life Course

- The lifetime cost of medical and non-medical care for a person with autism is estimated at $3.2 million (Ganz, 2006).

- This does not include the impacts on the family -- financial, social, and mental and physical health.
The World of Autism for the Family – Triple Jeopardy

- Autism has been shown to be the most stressful of all developmental disorders for the family system.
- Some family members manifest the “broader autism phenotype.”
- The risk of a second child with autism is between 4 and 10%, more heritable than schizophrenia or bipolar disorder.
Diversity of Family Experiences

- "He is all-consuming of our time, energy, patience. It can be emotionally and physically draining to be constantly vigilant of his emotional arousal levels. I cannot work outside the home. It is a full-time job caring for our son."

- "He will slap, hit, pull hair and moan. The hitting is the worst. He will walk up and hit a stranger."

- "The MESS. The noise. She still can’t wash her own hair. I WORRY all the time."
Diversity of Family Experiences

- “I’ve tried things and done things I never would have without him, such as running for school board and serving for 15 years. Having him has been a chance to grow in unexpected ways.”

- “She keeps us focused on what’s important in life – compassion and love – and helps us become stronger as a family.”

- “He is our son and we love him dearly. He has taught us much more than we ever teach him. Everything he learns makes us smile.”
Adolescents and Adults with Autism: The Impact of Family Caregiving

- Longitudinal study spanning 12 years (2000-2012), funded by the NIH.

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

- Aims: to investigate the course of change in autism during adolescence and adulthood, and its impact on the family.
Research Design

- Large sample (n=406 families).
- Wide age range – the “child” was age 10 - 52 at the beginning of the study.
- Macro-level measures every 18 months.
- Micro-level “daily diary study” over 8 days.
- Biomarkers of stress during diary study.
Daily Diary Study

- 8 days, telephone calls every evening, assess time use, daily stresses, positive events, mood, physical health.
- Comparison group from nationally representative sample of non-caregiving mothers.
- On days 2 – 5, participants collect 4 saliva samples each day to measure cortisol, a stress hormone.
“Marsha had another episode with her intestinal problems today. I had to drop everything and help her get through the pain by giving her water and restraining her. The extreme pain makes her hit her arms, so I have to keep her from hurting herself. She’s very strong and she incidentally hit me. Restraining her uses muscles that I don’t normally use and it causes pain for me as well. She has these episodes on most days, but not everyday, and I feel useless because I can’t make her feel better. We’ve been dealing with this for 5 years and we can’t seem to find any treatment to manage it. It limits what we can do as a family.”
“George found out that he will be starting a new job tomorrow. It’s been a stressful evening. My husband and I were having a conversation and the sound of our voices just set him off. The poor guy starts freaking out, saying, ‘What’s that? What’s going on?’ We had to stop what we were doing to get him to calm down. For a normal person, you could just say ‘Chill out. What’s your problem?’ But we can’t do that. All the time I spent calming him down and redirecting him kept me from starting my evening chores. And when he gets upset like that he also lashes out at his siblings and they start fighting too. A total snowball effect.”
Physiological Effects of Daily Stress

- Cortisol is a stress hormone that has a very characteristic pattern of daily expression.
- In healthy individuals, cortisol rises early in the day to help us “rev up” for the day’s challenges and declines thereafter.
- At the end of the day, cortisol is very low which allows us to get adequate rest.
- Dysregulation of cortisol has been linked to physical and mental health problems.
- We measured cortisol 4 x/day for 4 days as part of the diary study (days 2 - 5).
Hypoactivation of Cortisol

- A low level of cortisol is characteristic of chronic stress, such as post-traumatic stress disorder (PTSD).
- In mothers of children with autism, cortisol does not rise normally early in the day to help them “rev up” for the day’s challenges.
- Reflects the pattern of fatigue and stress documented in the daily diary study.
Bi-Directional Effects

- These data show the effect of the child’s behaviors and symptoms on the mother.

- We also have data to suggest that the emotional climate of the family has an effect on the child’s behaviors and symptoms.
Effects on the Child’s Symptoms and Behavior Problems

- **High levels of criticism** by parents predict significantly increasing repetitive behaviors in the son or daughter with autism 18 months later.

- **High levels of warmth** by parents predict significantly declining repetitive behaviors 18 months later.
Family Environment Predicts Repetitive Behaviors over 18 Months

- **Graph 1:**
  - Y-axis: Criticism
  - X-axis: Repetitive Behaviors
  - Line shows a positive correlation between repetitive behaviors and criticism.

- **Graph 2:**
  - Y-axis: Warmth
  - X-axis: Repetitive Behaviors
  - Line shows a negative correlation between repetitive behaviors and warmth.
New Services for Families?

- Psycho-educational interventions have been shown to reduce criticism and to increase warmth in family members of patients with schizophrenia, Alzheimer’s, Parkinson’s, asthma.

- These interventions have been linked to reduced relapse rates and symptoms.

- Possible application to autism??
Final Thoughts

- Although there is evidence that autism is a complex genetic disorder, the reciprocal effects of the family environment on the behavioral phenotype of autism should not be underestimated.
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