INTRODUCTION
Research has shown that caregivers of children with autism spectrum disorders have significantly higher levels of stress, depression and other mental health issues. These health issues negatively affect caregivers’ well-being and daily activities. It is important to look at the factors that may be contributing to stress as well as factors to help alleviate secondary health problems.

Recent research noted that individuals with some genotypes (short allele carriers of a serotonin reuptake transporter gene S-HTTLPR) are more vulnerable to stressors and depression than those with the long allele variant.

Purpose: This study used mixed methods and examined whether caregivers with varying levels of caregiving stress differ on perceptions of caregiving, genotype, and self-ratings of optimism.

RESEARCH DESIGN & METHODS
Caregivers were recruited at autism conferences in California and Wisconsin. A subset from this sample was used for data analysis.

Caregivers were invited to participate if they met the following criteria:
- Parenting a child with autism spectrum disorder who was 8-21 years of age
- Primary caregiver for the child

Participants: 11 Caucasian mothers ages 35-58 years with some level of higher education.

Procedures: Caregivers completed a blood draw for the genotype assay and a survey booklet. Caregivers were interviewed in person or over the phone using a semi-structured interview guide.

Surveys:
- LOT-R (Life Orientation Test- Revised): caregivers rated 10 statements on a 5-point Likert scale. Scores ranged from 18 to 36. Lower scores indicate a more optimistic life orientation.
- PSS (Perceived Stress Scale): caregivers rated 14 statements on a 5-point Likert scale. Scores ranged from 16.15-38.77. Higher scores indicate a higher level of perceived stress.

Analysis: Caregivers were grouped into short (s/s and s/l) and long allele groups (l/l). The relationship between genotype and PSS and optimism were examined via a t-test and a Spearman’s correlation.

Interviews were recorded and transcribed verbatim. Using open coding, analysis focused on the following interview questions:
- What are the rewarding parts of caregiving?
- Has caregiving enriched your life?
- What are the most stressful parts of caregiving?

RESULTS

- Genotype was not associated with PSS scores (t(4.77) = -.86, p = .43).
- Perceived stress was moderately correlated with optimism (r = .67, p = .024).

QUALITATIVE ANALYSIS

- Based on the correlation of perceived stress and LOT scores, participants were grouped into lower stress/higher optimism and higher stress/lower optimism groups.

- Interview data were examined to see whether these groups (less stress/more optimism vs. more stress/less optimism) experienced caregiving differently.

LOWER STRESS/HIGHER OPTIMISM GROUP
- Caregiver felt rewarded seeing their child participate in community and family activities or doing difficult tasks by overcoming their personal challenges related to autism characteristics. For example:
  - A child who showered without goggles over his eyes for the first time
  - A child participating in a competitive music event with typically developing peers

- Caregiver felt enriched by caregiving and felt that they grew from the experience.

Absolutely, I think that it has made me a more empathetic person, more patient, more observant, more kind…. a more spiritual person, it pretty much changed my whole life.

HIGHER STRESS/LOWER OPTIMISM GROUP
- Caregiver felt rewarded by successfully maintaining family harmony and functioning each day.

Just making sure everything’s accomplished, the day is over with and everyone’s done and we made it through another day. Everybody’s fine and no blood and no major spills and we’re all ok.

SIMILAR STRESSORS ACROSS GROUPS
- Unknowns - the future, are we doing the right thing?
- Constant Caregiving Demands
- Repetitive Tasks
- Child’s Behaviors (tantrums/meltdowns)
- Financial Issues
- Lack of Time for Significant Other
- Inability to Connect with Child

CONCLUSIONS
There was a significant relationship between the LOT-R scores and PSS scores. Caregivers who self-reported a lower level of stress also reported a more positive orientation (more optimistic) to their world, while caregivers who reported higher levels of stress also reported a less positive orientation (less optimistic).

Parenting a child with autism spectrum disorder who was 8-21 years of age

REFERENCES


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