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# Predictors of Caregiver Strain for Parents of Children with Autism Spectrum Disorder

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## Abstract

Parents of children with autism spectrum disorder (ASD) face higher levels of caregiver strain compared to parents of children with other disabilities. This study examined child clinical features that predict high levels of caregiver strain for 374 parents of children with ASD. Caregiver strain was measured using the Caregiver Strain Questionnaire (CGSQ) objective, subjective internalized, and subjective externalized subscales. Confirmatory factor analysis indicated an acceptable fit for the original CGSQ three-factor solution. The strongest child predictors across CGSQ subscales were: disruptive behavior for objective strain, autism severity and disruptive behavior for subjective internalized strain, and oppositional behavior and hyperactivity for subjective externalized strain. Individualized interventions that attend to specific elements of parental strain may reduce strain and improve family wellbeing.

### Keywords

Caregiver strain; Stress; Wellbeing; Disruptive behavior; Autism spectrum disorder

## Introduction

Parents of children with autism spectrum disorder (ASD) report high levels of caregiver strain (Cadman et al. 2012; Kirby et al. 2015) and challenges to mental health and well-being (Abbeduto et al. 2004; Cohrs and Leslie 2017; Khanna et al. 2011; Montes and Halterman 2007; Seymour et al. 2017). The concept of caregiver strain, sometimes referred to as caregiver “burden,” refers to the perceived negative effects of caring for a child with special needs. Experiences contributing to overall caregiver strain include financial hardship, disruption of routines, interference with work and career, fatigue, as well as feelings of social isolation, anger, worry, and sadness. Caregiver strain is widely accepted as a multidimensional construct comprised of both objective and subjective strain (Brannan et al. 1997). Objective strain is defined as how the caregiver perceives that caring for their child negatively affects observable aspects of daily life, including work, finances, and routines. In contrast, subjective strain describes the unobservable and emotional negative consequences of caregiving and is divided into two categories: internalized and externalized. Subjective internalized strain comprises the caregiver’s inwardly directed feelings of guilt, sadness, or worry that result from caring for their child with special needs. Subjective externalized strain describes a caregiver’s outwardly directed feelings of anger, resentment, and embarrassment related to their child.

Feelings of strain have a significant impact on how caregivers respond to their child's special needs and behavioral challenges, as well as how they access services (Brannan et al. 2003). In families with children with behavior challenges, caregiver strain has been identified as a critical factor in parent mental health (Sales et al. 2004) and is associated with poorer employment outcomes (Brannan et al. 2018). Studies of families of children with ASD suggest a direct link between the level of caregiver strain and the caregiver's psychological functioning and coping abilities. Seymour et al. (2013) observed that for caregivers of children with ASD, the severity of the child's behavior problems significantly impacted parental fatigue, which in turn led to ineffective coping strategies and increased parental stress. Caregiver strain was also found to be the most important predictor of mental health-related quality of life for families of children with ASD (Khanna et al. 2011) and has been associated with maladaptive coping strategies (Shivers et al. 2017). Given the negative consequences of elevated strain for caregivers and the family system, identification of child and family predictors of caregiver strain can lead to the development of targeted support for caregivers, including resources and mental health treatment, that will improve the overall quality of life for families of children with ASD.

Predictors of higher levels of caregiver strain for families of children with emotional and behavioral disorders, but not ASD, include increased complexity and severity of symptoms (Green et al. 2016; Molteni et al. 2017; Rockhill et al. 2013). For example, caregiver strain was observed to increase incrementally with the number of comorbid diagnoses of caregivers of children with ADHD (Rockhill et al. 2013). Externalizing behavior, conduct problems and, to a lesser extent, emotional difficulties have also been identified as significant predictors of all three types of strain (Brannan and Heflinger 2006; Green et al. 2016). Additionally, parents of children with conduct disorders, or comorbid conduct and emotional disorders, experience significantly greater caregiver burden than parents of children with emotional disorders alone (Meltzer et al. 2011). Similar findings have been observed in caregivers of children with developmental disabilities, where increased complexity and severity of the child's disability is associated with elevated caregiver strain (Stuart and McGrew 2009). Yet little is known about how the heterogeneous clinical presentation of ASD uniquely contributes to the three dimensions of caregiver strain. The few studies to examine this question in ASD have identified associations between child sensory difficulties, caregiver coping, and caregiver strain (Hand et al. 2018; Kirby et al. 2015; Shivers et al. 2017). The relationship between caregiver strain and child clinical features, including behavior problems, internalizing and externalizing symptomology, and adaptive behavior for families of children with ASD is still unknown.

Nuanced understanding of how the three dimensions of caregiver strain are uniquely tied to child features can differentially guide treatment and service delivery. For example, elevated subjective internalized strain may require specialized mental health and emotional support services for caregivers, whereas objective strain may indicate high levels of case management and increased respite and financial support. For some families, increased access to resources, such as respite care, may be sufficient for reducing stress and improving marital quality (Harper et al. 2013). Given that unmet needs are positively associated with caregiver strain, and specific types of strain put caregivers at a greater risk for maladaptive coping and mental health problems (Khanna et al. 2011; Shivers et al. 2017), it is important

to better understand specific contextual factors associated with greater objective, subjective internalized, and subjective externalized caregiver strain. Connecting specific child features to dimensional aspects of caregiver strain will guide models for assessing caregiver needs and providing targeted interventions.

The current study examined associations between child clinical features and caregiver strain for caregivers of children with ASD using the caregiver strain questionnaire (CGSQ) in a combined sample of youth with ASD who participated in one of three federally-funded, multi-site randomized trials (Bearss et al. 2015; King et al. 2009; Scahill et al. 2015). To examine associations between caregiver strain and clinical features in these youth with ASD, we used the CGSQ and clinical measures that were common across studies. Although the CGSQ has been used in samples of children with ASD (Khanna et al. 2012; Kirby et al. 2015), the factor structure was initially validated with children with emotional and behavioral disorders other than ASD (Brannan et al. 1997). Therefore, we evaluated the validity of the original factor structure as a prerequisite for pursuing additional analyses. To determine unique child profiles associated with each of the three dimensions of caregiver strain, we examined how child disruptive behaviors, comorbid psychiatric symptoms, repetitive behavior, and adaptive behavior skills were associated with the three dimensions of caregiver strain: objective, subjective internalized, and subjective externalized strain.

## Methods

### Participants

The sample included 374 children (aged 3–17 years) with ASD who participated in one of three multisite clinical trials: citalopram for repetitive behavior (King et al. 2009), guanfacine for hyperactivity (Scahill et al. 2015), and parent training for disruptive behaviors (Bearss et al. 2015). Diagnosis of ASD for participants was confirmed via clinical assessment and corroborated by the Autism Diagnostic Observation Schedule (ADOS; Lord et al. 2000), the Autism Diagnostic Interview-Revised (Rutter et al. 2003), or both. Additional entry criteria required participants to meet study-specific symptom severity thresholds and have a minimum mental age (e.g., receptive language ≥ 18 months). The medication studies required children to be drug-free at baseline (children on stable anticonvulsant treatment for seizures were allowed). The parent training study permitted children to be on psychotropic medication if stable with no planned changes for the duration of the six-month study. All three studies were approved by each site's institutional review board and written informed consent was obtained from parents or legal guardians prior to any study procedures.

### Procedure

Prior to randomization, participants received a comprehensive clinical evaluation to confirm ASD diagnosis and to collect pretreatment data. This initial evaluation included medical and developmental histories, parent questionnaires, clinician ratings, and cognitive assessment.

## Measures

Baseline demographic information included child age, sex, race, educational placement, maternal education, maternal age, and two-parent vs one-parent household. Diagnosis of autistic disorder, pervasive developmental disorder–not otherwise specified, or Asperger disorder was based on the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition-Text Revision (DSM-IV-TR, American Psychiatric Association 2000). IQ was assessed with the Abbreviated Stanford-Binet Fifth Edition (SB-V; Roid 2003) or the Mullen Scales of Early Learning (MSEL; Mullen 1995), according to the developmental level of the child. Given the use of different cognitive measures, children were classified as < 70 or ≥ 70.

**Caregiver Strain Questionnaire—**The CGSQ (Brannan et al. 1997) is a 21-item parent self-report measure that assesses the negative effects of caring for a child with special needs. Each item is rated from a score of 1 (not at all a problem) to 5 (very much a problem). It consists of three subscales (Objective Strain, Subjective Internalized Strain, and Subjective Externalized Strain), each expressed as the total of item responses in the subscale. The objective strain subscale measures parental impressions on the observable impacts of having a child with special needs—those related to work, finances, and daily routines. The subjective internalized strain subscale reflects the caregiver's inwardly directed feelings of sadness, fatigue and worry about the child's future. The subjective externalized strain subscale measures more outwardly directed experiences such as embarrassment, resentment and anger. The Global Score is the sum of all three subscale scores. Subscale scores at baseline were the primary variables of interest for this study.

**Aberrant Behavior Checklist—**The Aberrant Behavior Checklist (ABC; Aman et al. 1985; Kaat et al. 2014) is a 58-item parent-report measure of child behavior. Each item is rated on a scale from 0 (not a problem) to 3 (severe in degree). It includes five subscales: Irritability (tantrums, aggression, and self-injury; 15 items), Social Withdrawal (response to others, initiation of interaction; 16 items), Stereotypic Behavior (mannerisms and repetitive movements; 7 items), Hyperactivity/Noncompliance (hyperactivity and noncompliance; 16 items), and Inappropriate Speech (repetitive vocalizations; 4 items).

**Vineland Adaptive Behavior Scales, Second Edition, Parent/Caregiver Rating Form—**The Vineland-II (Sparrow et al. 2005) is a parent rating of adaptive behavior skills. Here we focus on the Socialization, Communication, and Daily Living Skills standard scores. The standard scores have a population mean of 100 and standard deviation of 15, with higher scores indicating better adaptive behavior skills.

**Screen for Emotional and Behavioral Disorders—**The Early Childhood Inventory (ECI; Gadow and Sprafkin 2000) and the Child and Adolescent Symptom Inventory (CASI; Gadow and Sprafkin 2005) are parent-rated scales based on DSM-IV symptoms. Items are scored from 0 (never) to 3 (very often). The ECI (for younger children) and CASI (school-age children and adolescents) have been used extensively in youth with ASD (Lecavalier et al. 2019). There are slight differences between the ECI and CASI based on age. The current study examined the following subscales: anxiety (ECI: 16 items; CASI:

20 items), attention-deficit/hyperactivity disorder (ADHD; 18 items), oppositional defiant disorder (ODD; 8 items), and pervasive developmental disorder (PDD; 12 items).

The Children's Yale Brown Obsessive–Compulsive Scale-Modified for Pervasive Developmental Disorders (CYBOCS-ASD) is a clinician-rating designed to evaluate the severity of repetitive behavior in children with ASD (Scahill et al. 2006). This modified version was derived from the CYBOCS, which measures the severity of obsessions and compulsions in children with obsessive–compulsive disorder (Scahill et al. 1997). The CYBOCS-ASD includes the five compulsion items: time spent, interference, distress, resistance to repetitive behavior, and control of repetitive behavior. Each of these items is rated from 0 (none) to 4 (extreme) for a total score ranging from 0 to 20.

## Data Analysis

Demographic and clinical measures were calculated as means with standard deviations, medians with interquartile ranges, or frequencies and percentages as appropriate. Confirmatory factor analysis (CFA) was conducted to determine whether the three factors of the original 21-item CGSQ adequately fit data collected from an ASD sample. We used a polychoric correlation matrix and an ordinary least squares (OLS) discrepancy function. To assess model fit, we applied root mean square error of approximation (RMSEA), comparative fit and Tucker-Lewis indexes (CFI and TLI), and chi-square goodness of fit (GOF) statistics. Acceptable index fits were defined at $< 0.1$ for RMSEA, $\geq 0.90$ for CFI and TLI (Browne and Cudeck 1992; Hu and Bentler 1999).

Differences in caregiver strain for parents of children with more vs. less impairment were evaluated. To maximize clinical interpretation of results, subgroups of youth with more vs. less impairment were defined by dichotomizing the sample at the 50th percentile on ABC subscales, CYBOCS-ASD, the pre-selected subscales from the ECI/CASI, and the Vineland. T-tests, adjusted for multiple comparisons using the Benjamini–Hochberg method, were used to test subgroup differences on parent-reported CGSQ subscale scores. Effect sizes, calculated as the difference in means over the pooled standard deviations, are additionally reported and interpreted as small (0.2), moderate (0.5), and large (0.8).

To identify associations between child characteristics and caregiver strain, we defined subgroups of parents as $\geq$ 75th percentile and $<$ 75th percentile on each CGSQ subscale in a series of logistic regression models. Again, subgroups of parents were dichotomized in this way to facilitate clinical interpretation of results. Bivariable logistic regression analyses, adjusted for age of child ($\geq$ 6 years versus $<$ 6 years), were used to get an initial reading on the association between impairment in youth and parents in the highest quartile on self-reported caregiver strain. Model results are presented as odds ratios (OR) with 95% confidence intervals (CI). Multivariable logistic models were constructed using forward selection, guided by the strength of the statistical associations in the bivariable calculations. To test the significance of each added variable, we used likelihood ratio. All Inferential analyses were performed using SAS v9.4 (Cary, NC).

## Results

Participants included 323 males and 51 females with ASD aged 3–17 years (mean = 7.04, SD = 3.13). Participant demographic and clinical characteristics are presented in Table 1. Results of the CFA indicated an acceptable fit for the original three-factor solution (RMSEA = 0.092, 90% CI 0.085–0.099; CFI = 0.90; TLI = 0.89; $\chi^2 = 773.1$, df = 186, $p < 0.001$). Although the TLI index was just under the conventional benchmark, we proceeded with the original CGSQ structure in all subsequent analyses to facilitate comparisons with other studies.

### Caregiver Strain in Youth with ASD

Table 2 shows that caregivers reported highest levels of strain on the subjective internalized subscale followed by the objective strain and the subjective externalized subscales. The correlations across subscales varied from Pearson *r* values of 0.31 to 0.65, with the highest correlation observed between subjective internalized and objective strain subscales. These results suggest that CGSQ subscales capture unique aspects of strain for caregivers of children with ASD. Maternal education, maternal age, and two-parent household status were not associated with any of the three CGSQ subscales.

### Caregiver Strain in Dichotomized Groups of Youth with ASD

Table 3 presents CGSQ subscale scores for children who scored at or above the median on child clinical measures compared to those below the median. Because higher scores indicate greater adaptive skill on the Vineland, the threshold for greater impairment is at or below the median versus above the median. The effect sizes ranged from medium to large for children with higher scores on measures of disruptive behavior (see Table 3). Parents of children at or above the median on the ABC subscales, ECI/CASI subscales, and CYBOCS-ASD reported higher levels of objective strain than caregivers of children rated below the median. Parents of children with higher scores on the ABC and ECI/CASI subscales and lower scores on the Vineland Communication and Socialization domains reported significantly higher scores on the CGSQ subjective internalized subscale. There were no statistically significant group differences on the caregiver reports of subjective externalized strain for children with more vs. less impairment.

### Clinical Predictors of Caregiver Strain

In order to identify predictors of very high levels of objective, subjective internalized, and subjective externalized strain (≥ 75th percentile), bivariable and multivariable logistic regression models were used and are presented in Table 4. In these models, we used the same dichotomized groups of children as predictors (see Table 3) and parents with self-rated CGSQ subscale scores at or above the highest quartile (≥ 75th percentile) as outcomes. As noted above, models were adjusted for child age.

The highest quartile on objective strain was associated with youth rated at or above the median on the ABC Irritability, Hyperactivity/Noncompliance, and Inappropriate Speech subscales, the ECI/CASI Anxiety, ADHD, and ODD subscales, and the CYBOCS-ASD. For example, youth at or above the median on the ABC Irritability and Hyperactivity/

Noncompliance subscales had 3 to 4 times higher odds of parents at or above the highest quartile on the CGSQ objective strain subscale, compared to those below the median (see Table 4). In the multivariable model, ABC Irritability, ABC Hyperactivity/Noncompliance, and ECI/CASI ADHD measures uniquely predicted parents in the highest quartile on objective strain subscale.

Parental membership in the high CGSQ subjective internalized strain group was predicted (odds ratios ranging from 1.5 to 2.0) by youth rated at or above the median on the ABC Irritability, Social Withdrawal, Stereotypy, and Hyperactivity/Noncompliance subscales, the ECI/CASI Anxiety, ADHD, and PDD subscales, and those rated at or below the median on the Vineland Communication domain (Table 4). In the multivariable model, the Vineland Communication domain, ECI/CASI Anxiety, ABC Irritability, and ABC Social Withdrawal subscales significantly and uniquely predicted parental membership in the highest quartile on subjective internalized strain.

Finally, the group in the highest quartile on the CGSQ subjective externalized strain was associated with ABC Social Withdrawal and Hyperactivity/Noncompliance subscales and the ECI/CASI ADHD and ODD subscales (odds ratios 1.5 to 2). In the multivariable model, ABC Hyperactivity/Noncompliance and ECI/CASI ODD subscale scores uniquely predicted parents in the highest quartile on the subjective externalized strain.

## Discussion

This study examined three dimensions of parent-reported caregiver strain as measured on the CGSQ in a well-characterized sample of children with ASD. Consistent with previous research in children with ASD (Khanna et al. 2011), we confirmed the three-factor solution of the CGSQ. Among the three subscales, caregivers of children with ASD reported the highest levels of subjective internalized strain, followed by objective strain, and then subjective externalized strain. Elevated levels of subjective internalized strain is consistent with other studies of families with children with ASD (Kirby et al. 2015) and emotional and behavioral disorders (Green et al. 2016). Other reports have also noted that parents of children with ASD express greater feelings of depression, anxiety, and pessimism about their child’s future than caregivers of children with intellectual disabilities (Abbeduto et al. 2004; Estes et al. 2009).

This is the first study to identify unique predictors of the three domains of caregiver strain for families of children with ASD. Caregiver report of objective strain was strongly associated with several aspects of child behavior. Parents of children rated at or above the median on all subscales of the ABC, on pre-selected subscales on the ECI/CASI (ADHD, oppositional defiant, hyperactivity and anxiety), and the CYBOCS-ASD were 3 to 4 times more likely to be in the highest quartile on objective strain. Additionally, irritability and hyperactivity/noncompliance emerged as unique predictors of caregivers scoring in the highest quartile on objective strain. These results suggest that in our sample of participants with ASD, elevated objective caregiver strain, such as disrupted family routines, disrupted family social activities, and interruption of personal time, was predicted most by child disruptive, externalizing behaviors. The impact of child disruptive behaviors, rather than

core features of ASD, on family daily lives has been reported in other samples of children with ASD (McStay et al. 2014). These results suggest that for families of children with ASD who exhibit the highest levels of disruptive behavior, including irritability and hyperactivity, an initial treatment strategy for reducing caregiver strain may be increased respite care, resources, case management, and parent training programs to support reduction of disruptive behavior (e.g., Bearss et al. 2015).

Predictors of the parents in the highest quartile on subjective internalized strain, which captures caregiver feelings of sadness, worry, guilt, and fatigue, included the ABC and ECI/CASI subscales. Subjective internalized strain was also associated with youth rated lower on adaptive socialization and communication skills. In the multivariable logistic model, however, only ABC Irritability and Social Withdrawal, ECI/CASI Anxiety, and Vineland Communication were retained as predictors of parents reporting the highest levels of subjective internalized strain. ABC Irritability and ECI/CASI Anxiety may be considered measures of reactivity. ABC Social Withdrawal and Vineland Communication may reflect characteristics more closely related to core features of ASD. Together, these results suggest that subjective internalized strain may be predicted most by severity of ASD core symptoms. In the CGSQ item-level descriptive statistics, the subjective internalized item rated highest by caregivers of children with ASD was being worried about the child's future, followed by feeling tired or strained. We hypothesize that impairments related to social interaction and communication, the core features of ASD, may cause more feelings of worry, and when combined with irritability, may lead to increased feelings of being taxed and tired. These results suggest that parents who report high levels of both disruptive behavior *and* impairment in communication and social interaction may benefit from emotional and mental health interventions to target strain related to feelings of sadness and worry, in addition to treatment and support explicitly related to their child's disruptive behavior.

Finally, subjective externalized strain, characterized by feelings of embarrassment, resentment, anger, and an inability to relate to the child, had the lowest average score for this sample of caregivers, in addition to the fewest predictors. Subjective externalized strain was associated with ABC Social Withdrawal and Hyperactivity/Noncompliance subscales and ECI/CASI ADHD and ODD subscales. Unique predictors of parents reporting the highest level of subjective externalized strain were high scores on measures of hyperactivity/noncompliance and ODD symptomology. In contrast to irritability, which can be described as a consistent, mild to moderate unpleasant mood that causes caregiving challenges, ODD symptomology describes the more extreme behaviors of opposition, active defiance, and aggression. It is perhaps not surprising then that ODD and hyperactivity, both particularly disruptive clinical profiles, result in more outwardly directed feelings of anger, resentment, and an inability to relate to the child. However, the subjective externalized strain subscale includes only four items, which may limit interpretation of the finding (Brannan et al. 2012). Best treatment practices for disruptive behavior disorders, including ODD, consist of parent training programs (e.g., Parent Management Training and Parent–Child Interaction Therapy; Eyberg et al. 2008) and recent evidence suggests that this type of treatment for children with ASD and disruptive behaviors is also effective in reducing feelings of subjective externalized strain (Iadarola et al. 2018).

### Strengths and Limitations

A strength of the current study is the availability of data from a large, well-characterized sample of children and adolescents with ASD. These treatment-seeking participants were enrolled in one of three clinical trials targeting different clinical features of ASD. Thus, the sample reflects a range of children with ASD. Nonetheless, this was a sample of convenience. The findings may not generalize to children with ASD whose parents are not seeking treatment or seeking treatment for other reasons. The current study did not evaluate past or current caregiver mental health conditions, such as depression or anxiety. Thus, it is not clear that parental expressions of sadness, fatigue and worry were necessarily caused by the child's diagnosis or behavior.

## Conclusions and Implications

Overall, results from this study suggest that distinct types of caregiver strain are predicted by unique behavioral characteristics of children with ASD. Objective strain as measured on the CGSQ was predicted by child disruptive behavior. In addition to disruptive behavior, subjective internalized strain was predicted by impaired social interaction and communication. Subjective externalized strain was predicted by oppositional and defiant behavior. These clinical profiles offer targets for treatment strategies to reduce parental strain and improve quality of family life. Interventions may include parent education, respite care, parent training, and medication in select cases. A recent meta-analysis supports the efficacy of parent training to reduce oppositional and defiant behavior in children with ASD (Postorino et al. 2017) and may also reduce parenting stress (Iadarola et al. 2018). Future research could test how intervention affects specific aspects of caregiver strain.

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**Table 1**

Demographic characteristics of children and caregivers

| Demographics | N | N (%) or Mean (SD) |
|---|---|---|
| Child age (years) | 374 | 7.04 ± 3.13 |
| Sex | 374 | |
| Male | | 323 (86.4%) |
| Female | | 51 (13.6%) |
| Race | 373 | |
| White | | 253 (67.8%) |
| Black | | 33 (8.9%) |
| Asian | | 21 (5.6%) |
| Hispanic | | 47 (12.6%) |
| Other | | 19 (5.1%) |
| DSM-IV-TR diagnosis | 374 | |
| Autistic disorder | | 293 (78.3%) |
| PDD-NOS | | 61 (16.3%) |
| Asperger disorder | | 20 (5.4%) |
| Education | 373 | |
| Regular class | | 195 (52.3%) |
| Regular school, special education program | | 131 (35.1%) |
| Special education school | | 28 (7.5%) |
| Other | | 19 (5.1%) |
| IQ | 364 | |
| < 70 | | 112 (30.8%) |
| ≥ 70 | | 252 (69.2%) |
| Maternal education | 333 | |
| High school or less | | 38 (11.4%) |
| Trade school/at least some college | | 235 (70.6%) |
| Advanced degree | | 60 (18%) |
| Mother’s age | 360 | 38.57 ± 7.16 |
| Study | 374 | |
| Parent training | | 176 (47.1%) |
| Citalopram | | 139 (37.2%) |
| Guanfacine | | 59 (15.8%) |

**Table 2**

Per item mean and individual item mean scores on CGSQ subscales

| | Mean (SD) |
|---|---|
| Objective strain subscale | 2.76 (0.8) |
| (1) Time interruption | 3.55 (1.19) |
| (2) Missed work/duties | 2.85 (1.22) |
| (3) Disrupted family routines | 3.14 (1.1) |
| (4) Doing without things | 2.63 (1.3) |
| (5) Negative health effects | 2.26 (1.25) |
| (6) Child in trouble | 1.29 (0.73) |
| (7) Financial strain | 2.53 (1.39) |
| (8) Less attention other family | 2.96 (1.22) |
| (9) Disrupt family relationships | 2.79 (1.26) |
| (10) Disrupt family activities | 3.45 (1.26) |
| (11) Feeling isolated | 2.95 (1.29) |
| Subjective internalized | 3.26 (0.87) |
| (12) Feeling sad or unhappy | 2.76 (1.2) |
| (16) Worried child future | 4.15 (1) |
| (17) Worried family future | 3.14 (1.35) |
| (18) Guilty child problem | 2.49 (1.4) |
| (20) Tired or strain | 3.67 (1.13) |
| (21) Toll on family | 3.33 (1.16) |
| Subjective externalized | 2.15 (0.6) |
| (13) Feeling embarrassed | 2.19 (1.21) |
| (14) Relating to child[a] | 3.26 (1.25) |
| (15) Anger toward child | 1.78 (0.99) |
| (19) Resentful toward child | 1.37 (0.75) |
| Global score | 8.17 (1.82) |

[a]Reverse-coded

**Table 3**

Mean scores on CGSQ subscales in youth with ASD divided at the median on ratings of child behavior

| Child measure | < 50th percentile on child rating | ≥ 50th percentile on child rating | P-value[1] | Effect size[3] |
|---|---|---|---|---|
| Objective strain | | | | |
| ABC | | | | |
| Irritability | 2.45 (0.77) | 3.07 (0.72) | < **0.001** | 0.83 |
| Social withdrawal | 2.62 (0.84) | 2.89 (0.76) | **0.001** | 0.35 |
| Stereotypy | 2.64 (0.80) | 2.86 (0.79) | **0.012** | 0.27 |
| Hyperactivity/noncompliance | 2.49 (0.74) | 3.01 (0.78) | < **0.001** | 0.68 |
| Inapp. speech | 2.62 (0.77) | 2.91 (0.81) | < **0.001** | 0.37 |
| ECI/CASI | | | | |
| Anxiety | 2.58 (0.80) | 2.94 (0.77) | < **0.001** | 0.46 |
| ADHD | 2.57 (0.73) | 2.96 (0.84) | < **0.001** | 0.51 |
| ODD | 2.53 (0.82) | 2.96 (0.75) | < **0.001** | 0.55 |
| PDD | 2.61 (0.84) | 2.91 (0.74) | < **0.001** | 0.38 |
| CYBOCS-ASD total | 2.62 (0.81) | 2.90 (0.78) | < **0.001** | 0.35 |
| Vineland[2] | | | | |
| Communication | 2.86 (0.83) | 2.69 (0.78) | 0.052 | 0.21 |
| Daily living | 2.75 (0.84) | 2.76 (0.77) | 0.946 | 0.01 |
| Socialization | 2.80 (0.83) | 2.72 (0.78) | 0.359 | 0.10 |
| Subjective internalized strain | | | | |
| ABC | | | | |
| Irritability | 3.09 (0.92) | 3.42 (0.79) | < **0.001** | 0.39 |
| Social withdrawal | 3.04 (0.88) | 3.42 (0.82) | < **0.001** | 0.45 |
| Stereotypy | 3.07 (0.85) | 3.41 (0.86) | < **0.001** | 0.40 |
| Hyperactivity/noncompliance | 3.08 (0.90) | 3.41 (0.81) | < **0.001** | 0.38 |
| Inapp. speech | 3.12 (0.84) | 3.40 (0.88) | **0.003** | 0.32 |
| ECI/CASI | | | | |
| Anxiety | 3.12 (0.86) | 3.38 (0.86) | **0.006** | 0.30 |
| ADHD | 3.11 (0.83) | 3.39 (0.89) | **0.003** | 0.33 |
| ODD | 3.15 (0.92) | 3.34 (0.82) | **0.046** | 0.22 |

| Child measure | < 50th percentile on child rating | ≥ 50th percentile on child rating | P-value[1] | Effect size[3] |
|---|---|---|---|---|
| PDD | 3.09 (0.86) | 3.42 (0.85) | < **0.001** | 0.40 |
| CYBOCS-ASD total | 3.21 (0.89) | 3.31 (0.85) | 0.273 | 0.11 |
| Vineland[2] | | | | |
| Communication | 3.41 (0.88) | 3.13 (0.83) | **0.003** | 0.33 |
| Daily living | 3.34 (0.90) | 3.18 (0.83) | 0.088 | 0.18 |
| Socialization | 3.35 (0.87) | 3.16 (0.86) | **0.046** | 0.22 |
| Subjective externalized strain | | | | |
| ABC | | | | |
| Irritability | 2.13 (0.52) | 2.17 (0.67) | 0.533 | 0.07 |
| Social withdrawal | 2.09 (0.58) | 2.19 (0.61) | 0.255 | 0.18 |
| Stereotypy | 2.13 (0.56) | 2.17 (0.63) | 0.564 | 0.06 |
| Hyperactivity/noncompliance | 2.11 (0.52) | 2.19 (0.67) | 0.466 | 0.13 |
| Inapp. speech | 2.10 (0.54) | 2.21 (0.65) | 0.255 | 0.18 |
| ECI/CASI | | | | |
| Anxiety | 2.08 (0.58) | 2.22 (0.62) | 0.156 | 0.24 |
| ADHD | 2.10 (0.53) | 2.21 (0.66) | 0.255 | 0.17 |
| ODD | 2.08 (0.54) | 2.22 (0.65) | 0.156 | 0.23 |
| PDD | 2.18 (0.57) | 2.13 (0.64) | 0.523 | 0.09 |
| CYBOCS-ASD total | 2.18 (0.60) | 2.12 (0.60) | 0.494 | 0.11 |
| Vineland[2] | | | | |
| Communication | 2.17 (0.61) | 2.12 (0.57) | 0.523 | 0.09 |
| Daily living | 2.17 (0.59) | 2.13 (0.60) | 0.533 | 0.07 |
| Socialization | 2.18 (0.58) | 2.11 (0.60) | 0.481 | 0.12 |

Bold values indicate statistical significance ($p < 0.05$)

[1] P-values adjusted for multiple comparisons using the Benjamini–Hochberg procedure

[2] CGSQ scores assessed at ≤ 50th versus > 50th percentile for Vineland

[3] Effect sizes are calculated as the difference in means divided by the pooled standard deviations. Values are interpreted as small (0.2), moderate (0.5), and large (0.8)

**Table 4**

Odds ratios for child variables predicting parents in the highest quartile on CGSQ subscales

| Child measures | Bivariable | | Multivariable | |
|---|---|---|---|---|
| | CGSQ ≥ 75th percentile OR (95% CI) | P-value | CGSQ ≥ 75th percentile OR (95% CI) | P-value |
| Objective strain | | | | |
| ABC, ≥ 50th percentile | | | | |
| Irritability | 3.57 (2.18, 5.84) | < **0.001** | 2.32 (1.32, 4.10) | **0.004** |
| Social withdrawal | 1.42 (0.89, 2.25) | 0.137 | | |
| Stereotypy | 1.51 (0.95, 2.39) | 0.081 | | |
| Hyperactivity/noncompliance | 4.24 (2.54, 7.07) | < **0.001** | 2.42 (1.32, 4.41) | **0.004** |
| Inapp. speech | 2.05 (1.29, 3.26) | **0.003** | | |
| ECI/CASI, ≥ 50th percentile | | | | |
| Anxiety | 1.75 (1.10, 2.78) | **0.018** | | |
| ADHD | 2.75 (1.71, 4.44) | < **0.001** | 1.86 (1.10, 3.15) | **0.020** |
| ODD | 2.25 (1.40, 3.64) | **0.001** | | |
| PDD | 1.19 (0.75, 1.87) | 0.458 | | |
| CYBOCS-ASD TOTAL, ≥ 50th percentile | 1.93 (1.22, 3.07) | **0.005** | | |
| Vineland, ≤ 50th percentile | | | | |
| Communication | 1.17 (0.74, 1.85) | 0.511 | | |
| Daily living | 1.14 (0.72, 1.82) | 0.570 | | |
| Socialization | 1.08 (0.68, 1.72) | 0.732 | | |
| Subjective internalized strain | | | | |
| ABC, ≥ 50th percentile | | | | |
| Irritability | 1.72 (1.10, 2.70) | **0.018** | 1.76 (1.09, 2.84) | **0.022** |
| Social withdrawal | 2.07 (1.30, 3.29) | **0.002** | 1.68 (1.01, 2.80) | **0.046** |
| Stereotypy | 1.80 (1.14, 2.84) | **0.012** | | |
| Hyperactivity/noncompliance | 1.66 (1.06, 2.60) | **0.028** | | |
| Inapp. speech | 1.52 (0.97, 2.37) | 0.068 | | |
| ECI/CASI, ≥ 50th percentile | | | | |
| Anxiety | 1.89 (1.20, 2.98) | **0.006** | 1.78 (1.09, 2.91) | **0.021** |

| Child measures | Bivariable | | Multivariable | |
|---|---|---|---|---|
| | CGSQ ≥ 75th percentile OR (95% CI) | P-value | CGSQ ≥ 75th percentile OR (95% CI) | P-value |
| ADHD | 1.90 (1.20, 2.98) | **0.006** | | |
| ODD | 1.31 (0.83, 2.05) | 0.244 | | |
| PDD | 2.00 (1.27, 3.15) | **0.003** | | |
| CYBOCS-ASD total, ≥ 50th percentile | 1.30 (0.83, 2.02) | 0.250 | | |
| Vineland, ≤ 50th percentile | | | | |
| Communication | 1.91 (1.21, 3.01) | **0.006** | 1.84 (1.12, 3.02) | **0.016** |
| Daily living | 1.55 (0.99, 2.44) | 0.058 | | |
| Socialization | 1.39 (0.89, 2.19) | 0.153 | | |
| Subjective externalized strain | | | | |
| ABC, ≥ 50th percentile | | | | |
| Irritability | 1.50 (0.96, 2.32) | 0.074 | | |
| Social withdrawal | 1.66 (1.05, 2.60) | **0.029** | | |
| Stereotypy | 1.42 (0.91, 2.21) | 0.121 | | |
| Hyperactivity/noncompliance | 2.11 (1.34, 3.31) | **0.001** | 1.85 (1.16, 2.96) | **0.010** |
| Inapp. speech | 1.42 (0.92, 2.21) | 0.117 | | |
| ECI/CASI, ≥ 50th percentile | | | | |
| Anxiety | 1.54 (0.99, 2.39) | 0.057 | | |
| ADHD | 1.68 (1.08, 2.61) | **0.022** | | |
| ODD | 1.93 (1.23, 3.03) | **0.004** | 1.67 (1.04, 2.68) | **0.033** |
| PDD | 0.99 (0.64, 1.53) | 0.964 | | |
| CYBOCS-ASD total, ≥ 50th percentile | 0.71 (0.46, 1.10) | 0.123 | | |
| Vineland, ≤ 50th percentile | | | | |
| Communication | 0.91 (0.59, 1.42) | 0.689 | | |
| Daily living | 0.94 (0.60, 1.47) | 0.780 | | |
| Socialization | 0.98 (0.63, 1.54) | 0.943 | | |

Bold values indicate statistical significance ($p < 0.05$)