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### Title

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### Permalink

<https://escholarship.org/uc/item/91g1k07n>

### Journal

Autism, 26(6)

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### Publication Date

2022-08-01

### DOI

10.1177/13623613211052108

Peer reviewed



Published in final edited form as:

*Autism*. 2022 August ; 26(6): 1460–1476. doi:10.1177/13623613211052108.

## Caregiver Strain among North American Parents of Children from the Autism Treatment Network Registry Call-Back Study

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### Abstract

Elevated caregiver strain is common and linked to poor health in parents of children with autism. Yet, little research has examined caregiver strain longitudinally and in geographically diverse samples of parents whose children have autism. This study aimed to (1) examine change in caregiver strain and (2) determine correlates of improved caregiver strain in North American parents of children with autism. This was a secondary analysis of data from the Autism Treatment Network Registry Call-Back Study, conducted from 2015–2017 on a random sample of children with ASD at 12 clinical sites in the U.S. or Canada. Child assessments and parent-reported questionnaires were completed at two time points one year apart. Caregiver strain was assessed with the Caregiver Strain Questionnaire. In total, 368 children had caregiver strain data at both times. Mean caregiver strain in parents did not significantly change between times 1 and 2 (mean difference=0.05,  $t(360)=0.1$ ,  $p=0.92$ ). Improved caregiver strain between times 1 and 2 was associated with improved child adaptive functioning and externalizing problem behaviors. Caregiver strain was persistent and multi-factorial. Parent training to manage challenging child behaviors and adaptively cope may benefit this vulnerable parent population.

### Keywords

adaptive functioning; autism; caregiver strain; North America; parents

### Introduction

Autism spectrum disorder (autism) is a chronic and complex neurodevelopmental condition (American Psychiatric Association, 2013; World Health Organization, 2004) that affects many children (Baxter et al., 2015; Maenner et al., 2020; Ofner et al., 2018). Families may experience positive and negative impacts in relationship to raising children with autism

(Kearney & Griffin, 2001; Taunt & Hastings, 2002). On the positive side, parents may feel their experience is a source of strength and family closeness, helps them to find purpose, and is an opportunity for hope and growth (Beighton & Wills, 2017; Kayfitz et al., 2010). Conversely, parents of children with autism often experience emotional and financial strain related to their caregiving duties (Altiere & von Kluge, 2009; Ganz, 2007; Zuckerman et al., 2014). Caregiver strain is, in turn, linked to poor health for both children with autism and their parents (Khanna et al., 2013; King et al., 2013; Lee & Shivers, 2019; Tint et al., 2017). Because parent and child health are inextricably linked (Case & Paxson, 2002), understanding which factors make parents of children with autism most susceptible to high caregiver strain and which factors help to reduce caregiver strain is vital to advancing interventions that promote family health and resilience.

Caregiver strain, including both objective strain (i.e., negative consequences of caregiving such as financial strain) and subjective strain (i.e., negative feelings that are internal to the caregiver or directed toward the child), has been assessed in parents of children with emotional and behavioral conditions including autism using the Caregiver Strain Questionnaire (Brannan et al., 1997; Khanna et al., 2012). Certain child factors such as younger age (Hand et al., 2018; Lee et al., 2019), disruptive behavior (Bradshaw et al., 2018; Brookman-Frazee et al., 2010; Iadarola et al., 2018), and severity of autism and/or sensory profile of autism symptoms (Hand et al., 2018; Kirby et al., 2015; Picardi et al., 2018; Stuart & McGrew, 2009) are related to higher caregiver strain. Parent factors associated with higher caregiver strain include younger age (Hand et al., 2018), living in a low income household (Hand et al., 2018), low quality of life (Khanna et al., 2011, 2013), maladaptive coping (Lee et al., 2019; McGrew & Keyes, 2014; Shivers et al., 2017; Stuart & McGrew, 2009), and limited social support (Khanna et al., 2012; Lee et al., 2019; Stuart & McGrew, 2009).

Limitations in prior research on caregiver strain in parents of children with autism highlight areas for additional research. The use of relatively small and geographically or otherwise homogeneous samples has, for example, limited the external validity of study findings (Bent et al., 2016; Bradshaw et al., 2018; Brookman-Frazee et al., 2010; Kirby et al., 2015; McGrew & Keyes, 2014; Stuart & McGrew, 2009). Cross-sectional study designs have further limited the ability to discern trends in caregiver strain among parents of children with autism (Hand et al., 2018; Khanna et al., 2012; Kirby et al., 2015; Lee et al., 2019; Picardi et al., 2018; Shivers et al., 2017). New knowledge of factors related to caregiver strain over time among diverse samples of parents of children with autism is, therefore, needed to help elucidate intervention targets and mechanisms that better optimize health for this vulnerable population.

### **Study Aims and Hypotheses**

This study aimed to (1) examine change in caregiver strain and (2) determine correlates (e.g., sociodemographic characteristics, child functioning and health characteristics, caregiver activation) of improved caregiver strain in a geographically diverse sample of North American parents of children with autism. For Aim 1, we hypothesized that on average caregiver strain would decrease during the study period because caregiver strain has been shown to be most elevated in parents around the time of diagnosis (Bent et al.,

2016; McGrew & Keyes, 2014). Parents of children with autism in this study were assessed on average several years following diagnosis, and the severity of autism—which may be linked to caregiver strain—has been shown to improve in some children over time (Szatmari et al., 2015; Waizbard-Bartov et al., 2020). For Aim 2, we hypothesized that improved caregiver strain would be related to certain sociodemographic characteristics such as higher socioeconomic status (e.g., household income) and better child functioning and health as indicated by factors such as adaptive functioning. The second hypothesis was based on past research demonstrating that parents of children with autism may experience greater burden if they have fewer resources and/or their children are significantly impacted by autism (Karst & Van Hecke, 2012; Picardi et al., 2018).

## Methods

### Design

We conducted a secondary analysis of data from the Autism Speaks Autism Treatment Network (ATN) Registry Call-Back Assessment study (RCBA). The ATN RCBA was initiated in 2015 to collect long-term, follow-up data on participants enrolled in the ATN registry (Murray et al., 2016). For the ATN RCBA, a random sample of ATN registry participants first enrolled in 2011–2012 or later was drawn from each of the 12 academic, hospital-affiliated clinics that were active in the ATN during 2015–2016 (Table 1). To be eligible, previous ATN assessment of the child must have occurred, and the child must have met *DSM-IV-TR* criteria for any pervasive developmental disorder or *DSM-V* criteria for autism during 2011–2016. ATN RCBA data were first collected in 2015 and then again one year later in 2016 or 2017. The mean time between the baseline ATN registry visit and the second annual ATN RCBA follow-up visit was 3.87 years ( $SD = 0.60$ ; range 2–5 years). The Institutional Review Board at each ATN RCBA site approved this research.

The ATN and ATN registry have both been previously described in greater detail (Coury et al., 2020; Murray et al., 2016; Perrin et al., 2016). Briefly, the ATN registry is a multisite database including developmental, behavioral, and health data on a convenience sample of children with autism who received care at an ATN clinical center in the U.S. or Canada. Exclusion criteria included a medical condition that precluded valid diagnostic testing (e.g., blindness, deafness), and parents had to be fluent in English or Spanish to be included.

### Sample

Our study's primary sample included 368 children who had caregiver strain data at both times. The 235 children who were missing caregiver strain data either at time 1 ( $n=8$ ) or time 2 ( $n=227$ ) were excluded from the primary study sample. For the primary study sample: mean child age at time 1 was 9.7 years ( $SD = 3.3$ ). Much of the sample was male (80.7%), was white and non-Hispanic (77.6%), had a primary caregiver with college education or more (57.1%), and was recruited from a clinical site in the United States (79.6%). Most children (71.5%) had a *DSM-IV-TR* or *DSM-5* diagnosis of autism, and the mean Autism Diagnostic Observation Scale (ADOS) score was 7.0 ( $SD = 2.1$ ). Average age of autism diagnosis was 5.4 years ( $SD = 3.1$ ), and the average time between autism diagnosis and RCBA visit (time) 1 was 3.7 years ( $SD = 0.7$ ). Table 2 shows other developmental,

behavioral, and health study sample characteristics. In comparing the primary study sample to participants who only provided caregiver strain data at time 1 ( $n=227$ ), statistically significant differences were found for the following characteristics: race and ethnicity ( $p = .02$ ), primary caregiver highest education level ( $p = .04$ ), geographic location ( $p = .005$ ), autism impact ( $p = .006$ ), externalizing problem behaviors ( $p = .01$ ), and sleep problems ( $p = .009$ ; Table 2). That is, participants who identified as white and non-Hispanic, had some college education or more, resided in Canada, had lower autism impact scores, reported less child externalizing problem behaviors, or reported less child sleep problems were more likely to provide data at RCBA times 1 and 2.

## Measures

**Caregiver Strain**—The Caregiver Strain Questionnaire (CGSQ) was used to assess parent-reported strain related to the target child with autism in the ATN RCBA at times 1 and 2 (Brannan et al., 1997). The CGSQ was originally developed to assess the impact of caring for a child with emotional and behavioral problems (Bickman et al., 1995; Brannan et al., 1997). The CGSQ has since been widely used to assess strain among caregivers of children with serious emotional and behavioral disorders and autism more specifically (Brannan et al., 1997; Khanna et al., 2012). The CGSQ consists of 21 items (Figure 1), rated on a five-point scale ranging from 1 (not at all a problem) to 5 (very much a problem). Only one item (“How well do you relate to your child”) was reverse scored. The CGSQ assesses the following three correlated caregiver strain dimensions: objective strain (i.e., negative consequences of caregiving such as financial strain and social isolation), internalized subjective strain (i.e., negative feelings that are internal to the caregiver such as worry and guilt), and externalized subjective strain (i.e., negative feelings directed toward the child such as anger or resentment). Given this study’s aims and hypotheses, to minimize bias due to multiple comparisons, and because past research has characterized differences in caregiver strain using the interrelated subscales in parents of children with ASD (Khanna et al., 2012; McGrew & Keyes, 2014; Shivers et al., 2017), we primarily focused on global caregiver strain using all 21 CGSQ items. In addition to using the global caregiver strain score in our analysis, we computed a binary variable of whether global caregiver strain had improved (decreased) versus stayed the same or worsened (increased) between time 1 and time 2. We found high internal consistency for the 21 CGSQ items ( $\alpha = 0.94$ ).

**Sociodemographic Characteristics**—Child age in years was assessed at time 1 during the ATN RCBA. Sex of the child and race/ethnicity (white and non-Hispanic, Hispanic, black and non-Hispanic, other race or multiracial and non-Hispanic) were assessed per data from the ATN Registry baseline. Household income (\$0–\$24,999; \$25,000–\$49,999; \$50,000–\$74,999; \$75,000–\$99,999; \$100,000+) in U.S. or Canadian dollars and primary caregiver education level (high school or less, some college, college or more) were also assessed from ATN Registry baseline. Whether the family lived in the U.S. or Canada was determined based on the ATN site they were recruited from.

## **Child Functioning and Health Characteristics**

**ATN Registry Baseline Age of Autism Diagnosis.:** Age of autism diagnosis was computed in years based on information available in the ATN Registry at baseline after individuals provided informed consent.

**ATN Registry Baseline Autism Diagnosis.:** ATN registry enrollment involved baseline assessments to confirm the child's autism diagnosis through clinical best estimate procedures involving the *DSM-IV-TR* or *DSM-V* (American Psychiatric Association, 2013; American Psychiatric Association (APA), 2000) and the Autism Diagnostic Observation Schedule (ADOS-2).

**ATN Registry Baseline Autism Severity.:** ADOS-2 Comparison scores, taken at the time of ATN registry enrollment, were used as an indicator of autism severity (Lord et al., 2012). Higher ADOS-2 Comparison scores indicated greater autism severity.

**ATN Registry Baseline Intellectual Functioning.:** Child intellectual functioning, also referred to as intelligence quotient (IQ), was measured at ATN enrollment through administration of a standardized cognitive assessment that yielded an overall summary score with a common metric. ATN cognitive assessments were selected in accordance with child presentation and needs, and included the Mullen Scales of Early Learning (Mullen, 1995), Bayley Scales of Infant Development-Third Edition (Bayley, 2006), Stanford-Binet Intelligence Scales-Fifth Edition (Roid, 2003), Differential Abilities Scales-Second Edition, Wechsler Preschool and Primary Scale of Intelligence-Third Edition (Wechsler, 2002), Wechsler Intelligence Scale for Children-Fourth Edition (Wechsler, 2003), Wechsler Abbreviated Scale of Intelligence (Wechsler, 1999), and the Leiter International Performance Scale-Revised (Roid & Miller, 2002).

**ATN RCBA Autism Symptoms.:** Parent rated autism symptoms were indexed by the Autism Impact Measure (AIM) Total Frequency score (Kanne et al., 2014). The AIM, which is a 25-item questionnaire using a two-week recall period and corresponding five-point response scales (frequency and impact), has been used to assess core autism symptoms in recent clinical trials (Fyre et al., 2018). Higher AIM scores indicated greater impact.

**ATN RCBA Adaptive Behavior.:** The adaptive behavior composite score from the Vineland Adaptive Behavior Scales—Second Edition survey interview form was used to assess level of adaptive behavior at ATN enrollment and to establish the presence of comorbid intellectual disability (Sparrow et al., 1984, 2005; Sparrow & Cicchetti, 1985). Higher scores indicated greater adaptive functioning across the following four domains: communication, daily living skills, socialization, and motor skills.

**ATN RCBA Child Behavior Problems.:** Total level of parent reported child externalizing and internalizing behavior problems was assessed using the Total Problems *T*-score from the widely used and validated Child Behavior Checklist (Achenbach & Ruffle, 2000; Cohen et al., 1985). Higher scores on the 113 items indicated more behavior problems.

**ATN RCBA Child Sleep Problems.:** Parent-reported child sleep problems were measured by the Children's Sleep Habits Questionnaire (CSHQ), which includes 45 items, with higher scores indicating greater frequency of behaviors associated with common child sleep difficulties (Owens et al., 2000).

**ATN RCBA Pediatric Quality of Life.:** Pediatric quality of life was measured by the PedsQL total score, with higher scores indicating better health-related quality of life (Varni et al., 2001). The PedsQL is a non-condition specific, 23-item questionnaire rated on a five-point response scale by parents.

**Caregiver Activation—**Level of parent skills, knowledge, and motivation as related to child health and disability status was measured with the total raw score from the Parent Activation Measure for Developmental Disabilities (PAM-DD), which includes 13-items rated on a four-point response scale (Ruble et al., 2018). Higher scores indicated greater parent activation.

## Analysis

Descriptive statistics were initially computed for all variables of interest (e.g., percentages for categorical variables, means for continuous variables). To address aim 1, we computed a *t*-test to examine mean change in global caregiver strain between times 1 and 2. We also computed a reliable change index to account for measurement error and better characterize change in global caregiver strain among our study's sample (Jacobson & Truax, 1991). Additionally, we compared the mean of each CGSQ item at time 1 in our study to the mean of each CGSQ item reported in the prior study by Khanna and colleagues (2012) using two sample *t* tests allowing for unequal variance. Bivariate tests were next computed to examine associations of global caregiver strain at time 1, global caregiver strain change between times 1 and 2, and improved global caregiver strain between times 1 and 2 (yes/no) with the sociodemographic, child functioning, and caregiver activation variables (Table 3). We additionally computed Spearman correlation coefficients for mean change in global caregiver strain and the other continuous variables (Appendix). The purpose of these bivariate analyses was to inform the subsequent multiple regression analysis for aim 2. That is, covariates for each multivariable model were determined according to statistically significant ( $p < .05$ ) bivariate analysis results. Three multivariable mixed effects linear/logistic regression models with a random intercept for site were fit including one for each global caregiver strain variable (global caregiver strain at time 1, mean change in global caregiver strain between time 1 and time 2, and improved versus stayed the same or worsened caregiver strain between time 1 and time 2; Table 4). The variance inflation factor (VIF) of all variables in each of the three models was computed, and each VIF was  $< 2$  indicating limited bias due to multicollinearity. Hypothesis tests for all statistical tests were two-sided, and the significance threshold was set to 0.05. All analyses were performed in Stata version 16 (StataCorp, 2019).

**Community Involvement:** Community members were not involved in the design of this study or the interpretation of its findings.



## Results

### Caregiver Strain

Global caregiver strain scores did change to some extent in most parents between the two times: increased in 47.9% of parents, decreased in 45.7% of parents, and stayed the same in 6.4% of parents. Still, mean global caregiver strain was 52.5 ( $SD = 16.4$ ) and 52.6 ( $SD = 17.2$ ) at times 1 and 2, respectively, and did not significantly differ between the two times (mean difference = 0.05,  $t(360) = 0.1$ ,  $p = 0.92$ ). The reliable change index also indicated that change in global caregiver strain between times 1 and 2 in the sample was not clinically significant. Objective caregiver strain did not differ significantly between times 1 and 2 (Time 1  $M = 27.4 \pm 10.3$ ; Time 2  $M = 27.6 \pm 6.1$ ; maximum score possible = 44), similar to both subjective internalized caregiver strain (Time 1  $M = 17.4 \pm 6.1$ ; Time 2  $M = 17.3 \pm 6.1$ ; maximum score possible = 24) and subjective externalized caregiver strain (Time 1  $M = 7.8 \pm 2.3$ ; Time 2  $M = 7.8 \pm 2.4$ ; maximum score possible = 16).

Means for each of the 21 CGSQ items at each time point along with the means on the CGSQ items from an earlier cross-sectional study by Khanna and colleagues (2012) are shown in Figure 1. The study by Khanna and colleagues (2012) included 304 primary caregivers of children with autism ages 18 years in West Virginia. In comparing time 1 CGSQ item means with CGSQ item means from the earlier study by Khanna and colleagues (2012), we found statistically significant mean differences in 15 items (Figure 1). In general, mean scores on these CGSQ items were significantly lower among this sample relative to the sample from the study by Khanna and colleagues (2012). Mean scores were significantly higher for this study's sample, however, for the item about financial strain (this study's  $M = 2.6 \pm 1.4$ , Khanna and colleagues study  $M = 2.4 \pm 1.4$ ;  $p = 0.043$ ) and for the item about relating to the child (this study's  $M = 3.2 \pm 1.5$ , Khanna and colleagues study  $M = 2.0 \pm 0.9$ ;  $p < .001$ ).

### Bivariate Associations of Caregiver Strain with Child and Family Characteristics

As shown in Table 3, bivariate results from unadjusted linear regression showed statistically significant associations of higher global caregiver strain (hereinafter caregiver strain) at time 1 with identifying as multiracial or another race (a race other than Black and non-Hispanic) versus white and non-Hispanic, living in Canada versus the U.S., having greater autism impact, more internalizing problem behaviors at time 1, more externalizing problem behaviors at time 1, poorer adaptive functioning at time 1, sleep problems at time 1, gastrointestinal problems at time 1, and poorer pediatric quality of life at time 1. Decreased mean caregiver strain between times 1 and 2 was associated with the following: higher adaptive functioning at time 1, improvement in adaptive functioning between times 1 and 2, decreases in internalizing problem behaviors between times 1 and 2, decreases in externalizing problem behaviors between times 1 and 2, and improvement in pediatric quality of life between times 1 and 2. Unadjusted logistic regression results showed that higher odds of decreased versus increased or constant caregiver strain between times 1 and 2 was associated with the following: household income \$25,000–\$49,999 or \$75,000–\$99,999 versus \$100,000 or more, improved adaptive functioning between times 1 and 2, decreased internalizing problem behaviors between times 1 and 2, decreased externalizing problem



behaviors between times 1 and 2, and improved pediatric quality of life between times 1 and 2.

### Multivariable Associations of Caregiver Strain with Child and Family Characteristics

Caregiver strain at time 1 was significantly associated with child race and ethnicity, geographic location, adaptive functioning at time 1, externalizing problem behavior at time 1, and pediatric quality of life at time 1 (Model 1; Table 4). Lower caregiver strain was significantly associated with adaptive functioning at time 1 ( $b = -0.13$ , 95% CI [-0.24, -0.02],  $p = .022$ ) and pediatric quality of life at time 1 ( $b = -0.19$ , 95% CI [-0.32, -0.06],  $p = .004$ ). Identifying as multiracial or another race (a race other than Black and non-Hispanic) versus White and non-Hispanic was associated with increased (worsened) caregiver strain ( $b = 5.64$ , 95% CI [0.33, 10.96],  $p = .037$ ), as was living in Canada versus the U.S. ( $b = 5.89$ , 95% CI [1.80, 9.97],  $p = .005$ ), and externalizing problem behavior at time 1 ( $b = 0.25$ , 95% CI [0.06, 0.44],  $p = .010$ ).

Both mean change in caregiver strain between times 1 and 2 and the adjusted odds of decreased (improved) versus increased or the same caregiver strain between times 1 and 2 were significantly associated with child adaptive functioning and externalizing problem behaviors (Models 2 & 3; Table 4). Improved adaptive functioning between times 1 and 2 was associated with decreased mean caregiver strain between times 1 and 2 ( $b = -0.24$ , 95% CI [-0.37, -0.11],  $p < .001$ ) and higher adjusted odds of decreased caregiver strain between times 1 and 2 (aOR = 1.06, 95% CI [1.03, 1.10],  $p = .001$ ). Increased externalizing problem behaviors between times 1 and 2 was associated with increased mean caregiver strain between times 1 and 2 ( $b = 0.33$ , 95% CI [0.16, 0.50],  $p < .001$ ), as well as lower adjusted odds of decreased caregiver strain (aOR = 0.95, 95% CI [0.91, 0.99],  $p = .02$ ). Improved pediatric quality of life between times 1 and 2 was additionally associated with decreased mean caregiver strain ( $b = -0.12$ , 95% CI [-0.21, -0.03],  $p = .008$ ). Annual household income of \$25,000–\$49,999 versus \$100,000 or more was associated with higher odds of decreased caregiver strain between times 1 and 2 (aOR = 2.90, 95% CI [1.36, 6.18],  $p = .01$ ).

## Discussion

This is one of the first studies to examine caregiver strain and its correlates in a geographically diverse sample of North American parents of children with autism over two time points. Contrary to our hypothesis for the first study aim, mean caregiver strain did not significantly change among parents. Still, caregiver strain did not remain the same for most parents over the two times. That is, nearly half of parents had an increase in caregiver strain. In terms of our second study aim, we found that increased child adaptive functioning between times 1 and 2 was significantly associated with improved (decreased) caregiver strain whereas increased child externalizing problem behavior between times 1 and 2 was significantly associated with poorer (increased) caregiver strain among parents. Increased pediatric quality of life between times 1 and 2 was significantly associated with improved caregiver strain; however, this was only found in the model where change in caregiver strain was treated as a continuous variable. This pattern of results was aligned

in part with our original hypothesis that improved caregiver strain would be related to improved child functioning and health. We did not, however, find significant associations between improved caregiver strain and most sociodemographic characteristics (e.g., primary caregiver education level), which was contrary to our hypothesis that higher resourced families would fare better.

Our study found no significant change in average caregiver strain over the approximately two-year RCBA study period among parents of children with autism; however, most parents had an increase or decrease in their global caregiver strain score. These results suggest that the use of mean caregiver strain may mask improvement or worsening in most parents, and that future research should endeavor to determine what clinically meaningful change in caregiver strain is for parents of children with autism. Similar to this study, another study conducted by McGrew and Keyes (2014) on caregiver strain during the first year after autism diagnosis found no change in parents. A prospective cohort study by Bent and colleagues (2016) also found that caregiver strain did not significantly change in a small sample of parents of young children with autism. Relative stability in caregiver strain among parents of children with autism may be due in part to the stability in core autism symptoms and adaptive functioning that many children are likely to experience (Szatmari et al., 2015; Waizbard-Bartov et al., 2020).

This study's findings regarding caregiver strain levels including on the subscales (e.g., objective strain) are fairly consistent with past research (Khanna et al., 2012; Shivers et al., 2017). CGSQ item means in our study at time 1 were generally lower than those in the study by Khanna and colleagues (2012). In the study by Khanna and colleagues (2012), CGSQ item level scores were mostly higher than those in the original study by Brannan and colleagues (1997) conducted among parents of children with emotional and behavioral disorders. The lower scores found in our study relative to the study by Khanna and colleagues (2012) may be in part due to differences between the two study samples. That is, the study conducted by Khanna and colleagues (2012) recruited caregivers of children with autism ages 18 years that only had one child with autism. The resulting sample was younger (< 10 years) suggesting that autism diagnosis may have been more recent, plausibly contributing to higher caregiver strain in the prior study. Other studies have shown parents of younger children with autism experience greater caregiver strain, particularly objective strain (Hand et al., 2018; Lee et al., 2019). Additional research is needed to establish clinical cut-offs for the CGSQ that may be used in clinical practice.

Because few studies have longitudinally examined caregiver strain, we will first discuss our study's findings regarding caregiver strain correlates (Aim 2) in relationship to relevant, past cross-sectional research beginning with a focus on sociodemographic characteristics. This study's results demonstrated higher caregiver strain for parents living in Canada versus the U.S. or identifying as multiracial or another race (a race other than Black and non-Hispanic) versus White and non-Hispanic. Though some past research investigating caregiver strain has recruited multinational parents of children with autism (Lee et al., 2019; Shivers et al., 2017), none of these studies have examined variability caregiver strain by nationality. Because this study's findings suggest that caregiver strain may be greater in Canadian parents of children with autism, further research—perhaps qualitative in nature—is needed

to determine why this difference exists. Our study's results suggest that caregiver strain is greater for some parents of color whose children have autism. This is likely due to myriad factors at various socioecological levels (e.g., family-clinician communication at the micro level, health insurance policies at the macro level) and their interplay. Although several prior studies have accounted for participant race and ethnicity, few have examined associations of race and ethnicity with caregiver strain (Brookman-Frazee et al., 2010; Khanna et al., 2012; Kirby et al., 2015; Lee et al., 2019; McGrew & Keyes, 2014; Shivers et al., 2017; Stuart & McGrew, 2009). Given the robust literature on racial and ethnic disparities in health care and health among individuals with autism (Bishop-Fitzpatrick & Kind, 2017; Magaña et al., 2015), future work is undoubtedly needed to further understand racial/ethnic differences in caregiver strain including the mechanisms by which these differences occur among parents of children with autism.

Regarding sociodemographic correlates of change and/or improvement in caregiver strain between times 1 and 2, household income (\$25,000–\$49,999 versus \$100,000 per year) was the only factor with a significant association. This finding runs counter to our hypothesis that better resourced families would be more likely to have improved caregiver strain. Yet, this finding is consistent with findings from the study by McGrew and Keyes (2014) that show higher household income is related to higher caregiver strain over time. Household income level may affect caregiver strain by way of other factors such as social support, community stigma, and/or coping mechanisms. That is, greater social support and other factors related to lower income levels may for example modify associations between caregiver strain and household income. Additional research is, therefore, needed to determine causal pathways between sociodemographic characteristics, child functioning, caregiver activation, and caregiver strain.

In terms of child health and functioning and caregiver activation correlates of caregiver strain at time 1, our study's results showed that poorer adaptive functioning, more externalizing problem behaviors, and poorer pediatric quality of life were each significantly associated with higher caregiver strain. This pattern of results is generally consistent with past research demonstrating that poorer child health and functional status is related to higher caregiver strain among parents of children with autism (Bent et al., 2016; Hand et al., 2018; Khanna et al., 2011; Stuart & McGrew, 2009). Caregiver activation as measured by the PAM-DD was not significantly correlated with caregiver strain in this study; however, past research has shown that other aspects of caregiver activation such as parent coping and unmet service needs are strongly associated with caregiver strain (Lee et al., 2019; McGrew & Keyes, 2014; Shivers et al., 2017). Future research should, therefore, endeavor to include an array of factors across socio-ecological levels that have been shown to influence caregiver strain to better understand the multifactorial nature of caregiver strain in parents of children with autism.

This study's findings showed that caregiver strain dynamically decreased between times 1 and 2 in relationship to increased adaptive functioning, decreased externalizing problem behaviors, and increased pediatric quality of life between times 1 and 2. The adjusted odds of improved caregiver strains between times 1 and 2 was also significantly associated with improved adaptive functioning and decreased externalizing problem behaviors between

times 1 and 2; however, increased pediatric quality life between times 1 and 2 did not maintain a significant association with improved caregiver strain. Together, these findings suggest that as child functioning and health improves, caregiver strain may be alleviated for parents of children with autism. Part of improvements in child functioning and health, as well as caregiver strain for some parents of children with autism may be due to greater adaptive coping and/or reduced maladaptive coping as suggested by prior research (Lee et al., 2019; McGrew & Keyes, 2014; Shivers et al., 2017). Other factors such as access to needed autism services for the child and programs to help parents manage challenging behavior may also be at play.

Several interventions have been used to reduce caregiver strain in parents of children with autism. Parent training and parent education programs, in particular, have been shown to decrease child disruptive behavior, parental stress, and caregiver strain (Bradshaw et al., 2018; Iadarola et al., 2018). Parent training programs such as those developed by Bearss and colleagues (2013, 2015), which use direct instruction to manage and ultimately reduce child disruptive behavior, have been shown to be more efficacious than parent education programs in reducing caregiver strain (Bearss et al., 2015; Bradshaw et al., 2018; Iadarola et al., 2018). The family peer advocate model, whereby trained parents of children with autism work to help other parents of children with autism to provide support and help them access needed services, has also been shown to decrease caregiver strain in racially and ethnically diverse parents of children with autism (Jamison et al., 2017). Programs designed to reduce stress, improve mental health, and promote resiliency in parents of children with autism may also be important to consider in terms of their potential to alleviate caregiver strain via adaptive coping (Da Paz & Wallander, 2017; Dykens et al., 2014; Kuhlthau et al., 2019). For this reason, the development of holistic autism programs using existing evidence-based models targeting behavior change in both children with autism and their parents may be a promising future direction. As more studies incorporate the CGSQ, comparative effectiveness research including meta-analysis will be possible to further determine which interventions and components yield the greatest benefits for children with autism and their parents.

### Limitations and Strengths

This study's findings should be interpreted with its main limitations and strengths in mind. Although this study provided data on caregiver strain at two times, we were unable to examine longer-term trends in caregiver strain. Despite the sample's geographic diversity, sociodemographic homogeneity may also limit the generalizability of study findings to lower resourced, racial/ethnically diverse, and rural populations of parents whose children have autism. Selection bias into the ATN Registry initially and the RCBA thereafter may have additionally biased our results insofar as individuals who self-select into registries may be better resourced with greater capacity than those who do not (Gliklich et al., 2014). Along the same lines, loss to follow-up between times 1 and 2 may have further biased our study's findings in a similar way. More specifically, among parents those: of color, with less education, residing in the U.S., with lower autism impact scores, whose children had more externalizing problem behaviors, or whose children had more sleep problems were most likely to be lost to follow-up after RCBA time 1. For these reasons, improved caregiver

strain may be slightly over-represented in our study's sample and factors associated with improved caregiver strain may be more relevant for better resourced families of children with autism. Conversely, average age of autism diagnosis in the study sample was older than five years, which would not be considered early diagnosis (< three years). Parents of children diagnosed earlier may, therefore, experience caregiver strain differently than those in this study. Nevertheless, we maintain that this study makes an important contribution to beginning to understand the dynamic nature of caregiver strain for parents of children with autism and has similar limitations to other survey studies of parents of children with autism (Kuhlthau et al., 2018; Langkamp et al., 2021). In addition, findings may be biased by how the CGSQ was worded. That is, the CGSQ includes questions about impact of caring for children with emotional and behavioral problems, not autism specifically. Last, we were unable to examine certain factors such as parent coping mechanisms, familial changes, quality of health care, and use of parent- or family-oriented interventions (e.g., family navigation, parent education and training programs) that may have also affected caregiver strain because these factors were not assessed in the RCBA study.

## Conclusion

Caregiver strain did not significantly change, on average, in this study suggesting that it is salient for many parents of children with autism over time. Interventions to ameliorate caregiver strain are, therefore, necessary and may include parent training and/or the use of peer advocates. Sociodemographic correlates of caregiver strain point to future research directions. Child health and functional characteristics associated with caregiver strain reinforce that child and parent improvements are dynamic and linked. Because caregiver strain was relatively high and related to child health and functioning, clinicians and advocates should continue endeavoring to connect parents to evidence-based programming during the diagnostic odyssey. Moreover, caregiver strain screening—like routine parental anxiety and depression screening in clinical practice—should be similarly considered in routine pediatric autism care.

## Acknowledgments

We have no known conflict of interest to disclose. This Network activity was supported by Autism Speaks and cooperative agreement UA3 MC11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital. This work was conducted through the Autism Speaks Autism Treatment Network. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, the U.S. Government, or Autism Speaks. This work was conducted through the Autism Speaks Autism Treatment Network serving as the Autism Intervention Research Network on Physical Health. Dr. Lindly's effort was also supported by grant # T32HS000063 from the Agency for Healthcare Research and Quality and the Southwest Health Equity Research Collaborative at Northern Arizona University (U54MD012388), which is sponsored by the National Institute on Minority Health and Health Disparities (NIMHD). We thank Christopher Moreno for his assistance with the data tables.

## Appendix

## Appendix

### Appendix.

Correlation Matrix of Global Caregiver Strain Change with Other Continuous Variables, Spearman Correlation Coefficients ( $n=244$ )

	CGS change	Child age	ADOS	IQ	AIM	Vineland	Vineland change	I-CBCL	I-CBCL change	E-CBCL	E-CBCL change	p
CGS change	1.00											
Child age	0.02	1.00										
ADOS	0.07	0.03	1.00									
IQ	-0.02	0.25***	-0.30***	1.00								
AIM	0.02	-0.10	0.04	-0.11	1.00							
Vineland	-0.08	-0.18*	-0.29***	0.50***	-0.11	1.00						
Vineland change	-0.24***	-0.07	0.02	-0.05	-0.05	-0.23***	1.00					
I-CBCL	-0.02	0.22***	-0.14*	0.24***	0.31***	-0.04	0.01	1.00				
I-CBCL change	0.19**	-0.11	0.06	-0.12	-0.12	0.01	-0.07	-0.41***	1.00			
E-CBCL	0.04	0.01	-0.06	0.08	0.37***	-0.20**	0.03	0.54***	-0.10	1.00		
E-CBCL change	0.25***	-0.04	0.07	-0.12	-0.10	-0.03	-0.10	-0.23***	0.36***	-0.28***	1.00	
CSHQ sleep problems	-0.03	-0.06	-0.06	-0.06	0.37***	-0.19**	0.05	0.37***	-0.12	0.42***	-0.12	
CSHQ sleep problems change	0.06	-0.02	0.02	0.03	-0.07	0.02	-0.10	-0.07	0.21**	-0.03	0.19**	
PedsQL	-0.002	-0.12	0.08	-0.08	-0.36***	0.25***	0.01	-0.50***	0.12	-0.44***	0.13*	
PedsQL change	-0.18**	0.14*	-0.08	0.18**	-0.01	0.05	0.15*	0.08	-0.29***	0.02	-0.27***	
PAM-DD	-0.10	0.07	0.10	0.03	0.16*	-0.06	0.05	-0.10	0.03	-0.04	0.05	

Note.

\*  $p < .05$ ,

\*\*  $p < .01$ ,

\*\*\*  $p < .001$ .

Age of autism diagnosis was not included due to amount of missing data. Abbreviations: ADOS, autism diagnostic observation schedule; AIM, Autism Impact Measure; ASD, autism spectrum disorder; CBCL, Child Behavior Checklist; CGS, Caregiver Strain; CHSQ, children's sleep habits questionnaire; CI, confidence interval; E-CBCL, externalizing problem behaviors CBCL; GI, gastrointestinal; I-CBCL, internalizing problem behaviors CBCL; PAM-DD, Patient Activation Measure for children with developmental disabilities; PedsQL, Pediatric Quality of Life Inventory.

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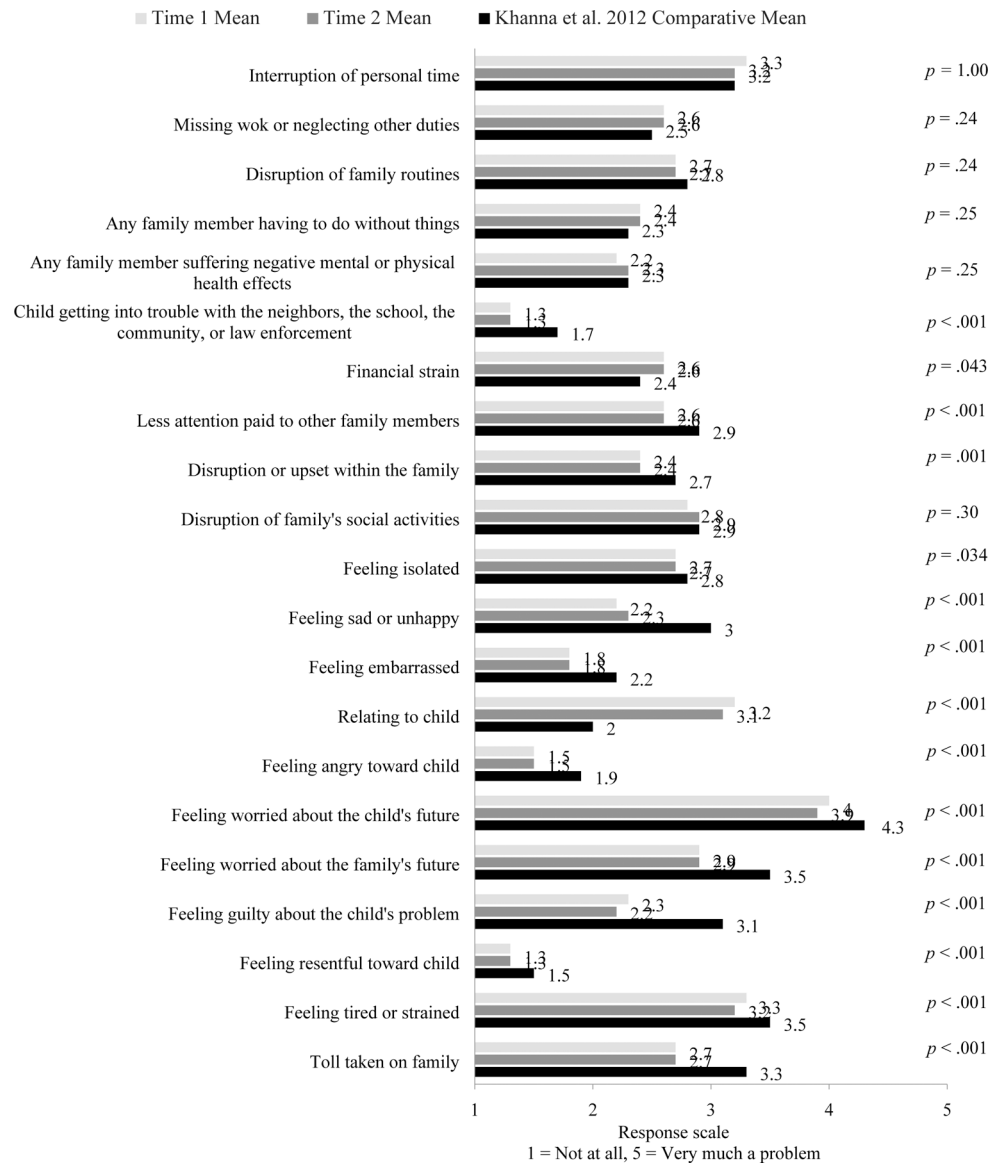
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**Figure 1.** shows the mean for each Caregiver Strain Questionnaire item at times 1 and 2 in this study and from a prior study among parents of children with autism conducted by Khanna and colleagues (2012). Higher ratings indicate more caregiver strain. The item “Relating to child” was reverse scored both studies. P-values were computed using two sample t tests allowing for unequal variance comparing each item mean at time 1 in this study with the corresponding item mean from the study by Khanna and colleagues.

**Table 1**

## Autism Treatment Network Registry Call-Back Assessment Sites

<b>Region</b>	<b>Site name</b>
Eastern	Lurie Center, Massachusetts General Hospital
	University of Pittsburgh Medical Center
	University of Rochester
	Children's Hospital of Philadelphia
Midwest	Cincinnati Children's Hospital Medical Center
	University of Missouri
	Nationwide Children's Hospital
Southern	Vanderbilt University Medical Center
	University of Arkansas for Medical Sciences
Western	Children's Hospital of Los Angeles
Canada	Toronto Holland Bloorview Kids Rehab, Surrey Place Centre, Hospital for Sick Children
	University of Alberta and Glenrose Rehabilitation Hospital

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Table 2

## Sample Characteristics

	Times 1 & 2			Time 1 Only			<i>p</i>
	<i>n</i>	Mean ( <i>SD</i> ) or percent	<i>n</i>	Mean ( <i>SD</i> ) or percent	<i>n</i>	Mean ( <i>SD</i> ) or percent	
<i>Sociodemographics</i>							
Age, years at RCBA Visit 1	368	9.7 (3.3)	227	9.5 (3.4)			.44
Male (Registry Baseline)	297	80.7%	177	78.0%			.46
Race (Registry Baseline)							.02
White, non-Hispanic	274	77.6%	143	65.9%			
Hispanic	25	7.1%	28	12.9%			
Black, non-Hispanic	18	5.1%	16	7.4%			
Another race or multiracial	36	10.2%	30	13.8%			
Household income (Registry Baseline)							.29
\$0.00–\$24,999	44	12.9%	40	19.0%			
\$25,000–\$49,999	72	21.1%	37	17.5%			
\$50,000–\$74,999	59	17.3%	30	14.2%			
\$75,000–\$99,999	38	11.1%	23	10.9%			
\$100,000+	85	24.9%	48	22.8%			
Did not wish to provide	41	12.0%	29	13.7%			
Unable to collect	2	0.6%	4	1.9%			
Primary caregiver education (Registry Baseline)							.04
High school or less	44	12.2%	43	20.0%			
Some college	111	30.8%	63	29.3%			
College or more	206	57.1%	109	50.7%			
Geographic location							.005
U.S. sites	293	79.6%	201	88.6%			
Canadian sites	75	20.4%	26	11.5%			
<i>Child Functioning and Health</i>							
Age of autism diagnosis, years (Registry Baseline)	88	5.39 (3.13)	55	5.76 (3.28)			.49
ASD diagnosis (Registry Baseline)							.07
Autism	263	71.5%	179	79.9%			

	Times 1 & 2			Time 1 Only			P
	n	Mean (SD) or percent	n	Mean (SD) or percent	Comparing times 1 & 2 to time 1 only		
Asperger's	33	9.0%	14	6.3%			
PDD-NOS	72	19.6%	31	13.8%			
ADOS severity score (Registry Baseline)	349	7.0 (2.1)	212	7.1 (2.0)	.40		
Cognitive ability (IQ) (Registry Baseline)	308	76.5 (22.9)	176	77.2 (22.5)	.72		
AIM Frequency from RCBA Visit 1	352	105.1 (18.5)	215	109.7 (21.3)	.006		
Vineland composite score from RCBA Visit 1	354	71.1 (0.8)	203	71.1 (0.95)	.97		
Vineland change from RCBA Visit 1 to 2	327	-0.003 (8.8)	0	N/A	N/A		
Behavioral problems							
Internalizing T-score from RCBA Visit 1	366	59.4 (10.2)	219	60.2 (10.1)	.38		
Internalizing T-score change from RCBA Visit 1 to 2	362	0.46 (8.0)	0	N/A	N/A		
Externalizing T-score from RCBA Visit 1	366	55.6 (10.7)	219	58.0 (11.4)	.01		
Externalizing T-score change from RCBA Visit 1 to 2	362	-1.4 (7.1)	0	N/A	N/A		
CSHQ sleep problems from RCBA Visit 1	367	44.1 (8.5)	224	46.1 (9.8)	.009		
CSHQ sleep problems change from RCBA Visit 1 to 2	367	-0.76 (6.0)	0	N/A	N/A		
GI problems	151	42.3%	84	39.3%	.48		
GI problems change from RCBA Visit 1 to 2					.99		
No GI problems both times	176	50.0%	4	66.7%			
GI problems both times	107	30.4%	2	33.3%			
No GI problems Visit 1 but GI problems at Visit 2	28	8.0%	0	0.0%			
GI problems at Visit 1 but no GI problems at Visit 2	41	11.7%	0	0.0%			
PedsQL total scale score from RCBA Visit 1	363	63.7 (16.5)	226	63.0 (15.6)	.63		
PedsQL total scale score change from RCBA Visit 1 to 2	363	-0.52 (12.3)	0	0	N/A		
<i>Caregiver Activation</i>							
PAM-DD from RCBA Visit 1	365	38.4 (12.8)	226	38.2 (11.6)	.81		

Note. Some percentages may not sum to 100 due to rounding. Fisher's exact or t-tests were used to compare data on the primary sample (both times) to data from those who only participated at time 1. Abbreviations: ADOS, autism diagnostic observation schedule; AIM, Autism Impact Measure; ASD, autism spectrum disorder; CBCL, Child Behavior Checklist; CGS, Caregiver Strain; CHSQ, children's sleep habits questionnaire; GI, gastrointestinal; N/A, not applicable; PAM-DD, Patient Activation Measure for children with developmental disabilities; PDD-NOS, pervasive developmental disorder - not otherwise specified; PedsQL, Pediatric Quality of Life Inventory; RCBA, Registry Call-Back Assessment; U.S., United States.



Table 3

## Bivariate Associations with Global Caregiver Strain

	CGS at Time 1 [95% CI]	<i>p</i>	CGS Change Times 1 & 2 [95% CI]	<i>p</i>	Odds CGS Decreased (vs. Increased or Same) Times 1 & 2 [95% CI]	<i>p</i>
<i>Sociodemographics</i>						
Child age, years at RCBA Visit 1	-0.27 [-0.78, 0.25]	.30	0.28 [-0.05, 0.61]	.10	0.94 [0.88, 1.01]	.07
Sex of child: Male (Registry Baseline)	-1.50 [-5.80, 2.80]	.49	-2.19 [-4.95, 0.56]	.12	1.20 [0.71, 2.04]	.50
Child race (Registry Baseline)						
White, non-Hispanic	Referent		Referent		Referent	
Hispanic	1.22 [-5.58, 8.02]	.73	-1.30 [-5.75, 3.16]	.57	1.07 [0.46, 2.51]	.88
Black, non-Hispanic	-4.57 [-12.35, 3.20]	.25	1.12 [-3.87, 6.12]	.66	0.58 [0.21, 1.60]	.30
Another race or multiracial	8.01 [2.20, 13.83]	.007	0.68 [-3.05, 4.41]	.72	1.17 [0.57, 2.38]	.67
Household income (Registry Baseline)						
\$0.00–\$24,999	-1.09 [-7.23, 5.05]	.73	-2.63 [-6.53, 1.27]	.19	1.71 [0.81, 3.62]	.16
\$25,000–\$49,999	-0.11 [-5.39, 5.17]	.97	-2.18 [-5.52, 1.16]	.20	2.42 [1.26, 4.63]	.01
\$50,000–\$74,999	1.13 [-4.47, 6.72]	.68	-0.07 [-3.59, 3.46]	.97	1.30 [0.65, 2.56]	.46
\$75,000–\$99,999	1.06 [-5.40, 7.53]	.75	-3.48 [-7.55, 0.60]	.09	2.24 [1.02, 4.93]	.04
\$100,000+	Referent		Referent		Referent	
Primary caregiver education (Registry Baseline)						
High school or less	-3.23 [-8.61, 2.14]	.24	1.17 [-2.29, 4.62]	.51	1.20 [0.62, 2.32]	.59
Some college	-0.08 [-3.93, 3.77]	.97	-0.91 [-3.37, 1.54]	.47	1.17 [0.73, 1.86]	.52
College or more	Referent		Referent		Referent	
Geographic location						
U.S. sites	Referent		Referent		Referent	
Canadian sites	5.29 [1.12, 9.47]	.013	1.58 [-1.11, 4.27]	.25	0.67 [0.39, 1.13]	.13
<i>Child Functioning and Health</i>						
Age of autism diagnosis, years (Registry Baseline)	-0.11 [-1.21, 1.00]	.85	0.25 [-0.43, 0.94]	.46	0.91 [0.79, 1.05]	.22
ASD diagnosis (Registry Baseline)						
Autism	Referent		Referent		Referent	
Asperger's	3.35 [-2.62, 9.31]	.27	0.27 [-3.54, 4.08]	.89	0.89 [0.43, 1.85]	.75
PDD-NOS	1.49 [-2.86, 5.84]	.50	-2.52 [-5.29, 0.26]	.08	1.14 [0.67, 1.93]	.63
ADOS severity score (Registry Baseline)	-0.41 [-1.25, 0.43]	.34	0.22 [-0.32, 0.77]	.42	0.92 [0.83, 1.02]	.13

	CGS at Time 1 [95% CI]	p	CGS Change Times 1 & 2 [95% CI]	p	Odds CGS Decreased (vs. Increased or Same) Times 1 & 2 [95% CI]	p
Cognitive ability (IQ) (Registry Baseline)	0.02 [-0.06, 0.10]	.67	-0.03 [-0.08, 0.02]	.28	1.01 [1.00, 1.02]	.25
AIM Frequency at RCBA Visit 1	0.20 [0.11, 0.30]	<.001	0.01 [-0.05, 0.07]	.66	1.00 [0.99, 1.02]	.55
Vineland composite score at RCBA Visit 1	-0.24 [-0.35, -0.13]	<.001	-0.10 [-0.17, -0.02]	.01	1.01 [1.00, 1.03]	.05
Vineland change RCBA Visit 1 to 2	-	-	-0.28 [-0.42, -0.15]	<.001	1.05 [1.02, 1.08]	.001
Behavioral problems						
Internalizing CBCL T-score at RCBA Visit 1	0.56 [0.40, 0.71]	<.001	-0.01 [-0.12, 0.10]	.85	1.01 [0.99, 1.03]	.40
Internalizing CBCL T-score RCBA Visit 1 to 2	-	-	0.23 [0.09, 0.36]	.001	0.96 [0.93, 0.98]	.001
Externalizing CBCL T-score at RCBA Visit 1	0.59 [0.44, 0.74]	<.001	-0.03 [-0.13, 0.08]	.62	1.00 [0.98, 1.02]	.73
Externalizing CBCL T-score RCBA Visit 1 to 2	-	-	0.42 [0.27, 0.57]	<.001	0.93 [0.90, 0.96]	<.001
CSHQ sleep problems at RCBA Visit 1	0.53 [0.33, 0.72]	<.001	-0.05 [-0.17, 0.08]	.48	1.01 [0.99, 1.03]	.45
CSHQ sleep problems RCBA Visit 1 to 2	-	-	0.17 [-0.02, 0.35]	.07	0.99 [0.95, 1.02]	.51
GI problems at RCBA Visit 1	6.52 [3.10, 9.94]	<.001	0.24 [-1.99, 2.47]	.83	1.04 [0.68, 1.60]	.84
GI problems change RCBA Visit 1 to 2	-	-	-	-	-	-
No GI problems both times	-	-	Referent	Referent	Referent	
GI problems both times	-	-	0.39 [-2.14, 2.92]	.76	0.89 [0.55, 1.46]	.66
No GI problems Visit 1 but GI problems at Visit 2	-	-	0.46 [-3.72, 4.63]	.83	0.62 [0.27, 1.43]	.27
GI problems Visit 1 but no GI problems at Visit 2	-	-	0.38 [-3.21, 3.98]	.83	1.12 [0.56, 2.24]	.74
PedsQL total scale score at RCBA Visit 1	-0.41 [-0.51, -0.32]	<.001	0.02 [-0.04, 0.09]	.50	0.99 [0.98, 1.01]	.33
PedsQL total scale score change RCBA Visit 1 to 2	-	-	-0.21 [-0.30, -0.12]	<.001	1.03 [1.01, 1.05]	.001
<i>Caregiver Activation</i>						
PAM-DD at RCBA Visit 1	0.03 [-0.10, 0.17]	.62	-0.04 [-0.13, 0.04]	.30	1.02 [1.00, 1.04]	.13

Note. – Not included in the analysis given temporal nature of the variable. Abbreviations: ADOS, autism diagnostic observation schedule; AIM, Autism Impact Measure; ASD, autism spectrum disorder; CBCL, Child Behavior Checklist; CGS, Caregiver Strain; CHSQ, children's sleep habits questionnaire; CI, confidence interval; GI, gastrointestinal; PAM-DD, Patient Activation Measure for children with developmental disabilities; PDD-NOS, pervasive developmental disorder – not otherwise specified; PedsQL, Pediatric Quality of Life Inventory; RCBA, Registry Call-Back Assessment; U.S., United States.

Table 4

## Multivariable Associations with Global Caregiver Strain

	Model 1 (n = 310)	Model 2 (n = 313)	Model 3 (n = 252)	
	Global CGS Time 1 [95% CI]	Change in CGS Times 1 & 2 [95% CI]	Odds Global CGS Decreased (vs. Increased or Same) Times 1 & 2 [95% CI]	P
	P	P	P	
Constant	45.26 [22.97, 67.54]	0.65 [-0.46, 1.77]	0.49 [0.29, 0.83]	.01
<i>Sociodemographics</i>				
Race (Registry Baseline)				
White, non-Hispanic	Referent	-	-	-
Hispanic	1.68 [-4.73, 8.10]	-	-	-
Black, non-Hispanic	-3.24 [-10.13, 3.66]	-	-	-
Another race or multiracial	5.64 [0.33, 11.00]	-	-	-
Household income (Registry Baseline)				
\$0.00-\$24,999	-	-	2.06 [0.87, 4.89]	.10
\$25,000-\$49,999	-	-	2.90 [1.36, 6.18]	.01
\$50,000-\$74,999	-	-	1.41 [0.65, 3.07]	.39
\$75,000-\$99,999	-	-	1.35 [0.51, 3.54]	.55
\$100,000+	-	-	Referent	
Geographic location				
U.S. sites	Referent	-	-	-
Canadian sites	5.89 [1.80, 9.97]	-	-	-
<i>Child Functioning and Health</i>				
AIM Frequency RCBA Visit 1	0.03 [-0.07, 0.12]	-	-	-
Vineland at RCBA Visit 1	-0.13 [-0.24, -0.02]	-	-	-
Vineland change RCBA Visit 1 to 2	-	-0.24 [-0.37, -0.11]	1.06 [1.03, 1.10]	.001
Internalizing CBCL T-score at RCBA Visit 1	0.12 [-0.09, 0.33]	-	-	-
Internalizing CBCL T-score RCBA Visit 1 to 2	-	0.04 [-0.11, 0.18]	0.99 [0.96, 1.03]	.78
Externalizing CBCL T-score at RCBA Visit 1	0.25 [0.06, 0.44]	-	-	-
Externalizing CBCL T-score RCBA Visit 1 to 2	-	0.33 [0.16, 0.50]	0.95 [0.91, 0.99]	.02
CSHQ sleep problems at RCBA Visit 1	0.07 [-0.15, 0.29]	-	-	-
GI problems at RCBA Visit 1	-	-	-	-

	Model 1 (n = 310)		Model 2 (n = 313)		Model 3 (n = 252)	
	Global CGS Time 1 [95% CI]	p	Change in CGS Times 1 & 2 [95% CI]	p	Odds Global CGS Decreased (vs. Increased or Same) Times 1 & 2 [95% CI]	p
Yes	2.35 [-1.07, 5.77]	.18	-	-	-	-
No	Referent		-	-	-	-
GI problems at RCBA Visit 1 to 2						
No GI problems both times	-	-	-	-	-	-
GI problems both times	-	-	-	-	-	-
No GI problems Visit 1 but GI problems at Visit 2	-	-	-	-	-	-
GI problems Visit 1 but no GI problems at Visit 2	-	-	-	-	-	-
PedsQL total scale score at RCBA Visit 1	-0.19 (-0.32, -0.06)	.004	-	-	-	-
PedsQL total scale score RCBA Visit 1 to 2	-	-	-0.12 [-0.21, -0.03]	.008	1.01 [0.99, 1.03]	.34
Wald $\chi^2$	(11) 103.51		(4) 56.76		(8) 29.40	
Probability > $\chi^2$	< .001		< .001		< .001	

Note. A random intercept for site was included in each multivariable model to account for potential clustering within sites.

Abbreviations: ADOS, autism diagnostic observation schedule; AIM, Autism Impact Measure; ASD, autism spectrum disorder; CBCL, Child Behavior Checklist; CGS, Caregiver Strain; CHSQ, children's sleep habits questionnaire; CI, confidence interval; GI, gastrointestinal; PAM-DD, Patient Activation Measure for children with developmental disabilities; PDD-NOS, pervasive developmental disorder - not otherwise specified; PedsQL, Pediatric Quality of Life Inventory; RCBA, Registry Call-Back Assessment; U.S., United States.