

## **Racial and Ethnic Differences in Behavioral Problems and Medication Use Among Children with Autism Spectrum Disorders**

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**Abstract** (322 words)

We examined racial and ethnic differences in the prevalence of behavioral problems measured by the Child Behavioral Checklist (CBCL), sleep disturbances measured by the Child Sleep Habits Questionnaire (CSHQ), and medication use among children with Autism Spectrum Disorders (ASD). We analyzed data for 2,576 children diagnosed with ASD ages 6 to 18 years old from the Autism Treatment Network (ATN) dataset. Multivariable logistic regression accounting for age, gender, DSM-IV-TR ASD diagnosis (Autistic Disorder, PDD-NOS, Asperger's Disorder), and parents' education did not show any racial or ethnic differences in Behavioral Challenges, Conduct Problems, or Sleep Disturbances for any of the groups, but Black children had lower odds of Total Problem Behaviors and Asian children had lower odds of Hyperactivity compared to White children. As a group, racial and ethnic minority children had lower odds of Total Problem Behaviors and Conduct Problems compared to White children. Hispanic children had lower odds of medication use for Behavioral Challenges, Total Problem Behaviors, Hyperactivity, and Conduct Problems. Asian children had lower odds of medication use for Behavioral Challenges, Total Problem Behaviors, and Hyperactivity; and had close to lower odds in medication use for Conduct Problems. Black children had lower odds for medication use for Total Problem Behaviors only. As a group, racial and ethnic minority children had lower odds for medications use for Behavioral Challenges, Total Problem Behaviors, Hyperactivity, and Conduct problems, but not for Sleep Disturbances. While these results are consistent with previous studies showing that White children are significantly more likely to receive psychotropic medication compared to children from racial

and ethnic minority groups, we found no such differences for sleep challenges, suggesting that they are more consistently identified and equitably treated than other behavioral problems associated with ASD. We draw upon Andersen's (1995) Behavioral Model of Healthcare Use to suggest predisposing, enabling, and needs factors that may contribute to this pattern of racial and ethnic differences in the use of medications among children ASD.

*Keywords: challenging behaviors; healthcare disparities; psychotropic medication use; sleep disturbances*

## **Introduction**

Behavioral problems such as self- and other- injurious behavior and aggressiveness, severe temper tantrums, irritability, and hyperactivity are common among children with Autism Spectrum Disorders (ASD) (Bauminger, Solomon, & Rogers, 2010; Leyfer et al., 2006; Matson & Servantes, 2014; Simonoff, et al., 2008; Soke et al., 2017; Zablotsky, et al., 2015), significantly impacting children's and families' quality of life. Although behavioral and mental health problems are often addressed by psychopharmacological means, as a population, children with ASD have considerable variability in psychotropic medication use from 27% to 83%. (Coury et al., 2012; Frazier et al., 2011; Gerhard, Chavez, Olfson, & Crystal, 2009; Logan et al., 2012; Mandell et al., 2008; Rosenberg et al., 2010; Spencer et al., 2013; Oswald & Sonenklar, 2007). The causes of such variability are poorly understood, and much remains unknown about racial and ethnic differences in the use of psychotropic medication for behavioral problems in children with ASD. It is currently unclear whether there are racial and ethnic differences in the prevalence, severity, and range of behavioral problems associated with ASD, or whether parents' cultural interpretations of these problems have an impact on psychotropic medication management. We also don't know whether physician biases are a factor, i.e. whether there are differences in clinician thresholds for decisions regarding psychotropic medication use for children from different racial and ethnic groups, as has been documented for other conditions (e.g. Goyal et al., 2015).

As a first step in addressing this knowledge gap, we examined racial and ethnic differences in the prevalence of behavioral problems (e.g. externalizing behaviors such as aggressiveness), sleep disturbances, and psychotropic medication use among 6 to 18 years old children and youth who were enrolled in the ATN registry between March 2008 and March

2016. Specifically, we evaluated racial and ethnic differences in the rates of behavioral problems measured by the Child Behavioral Checklist (CBCL, Achenbach & Rescorla, 2001; Rescorla et al., 2007), sleep disturbances measured by the Child Sleep Habits Questionnaire (CSHQ, Owens, Spirito, & McGuinn, 2000), and clinician-confirmed medication use among 6 to 18-year-old children diagnosed with ASD (APA, 2000).

Although psychopharmacological interventions are routinely used for behavioral problems associated with ASD (McDougle et al., 2008), it is considered preferable in clinical practice that such problems are first addressed by functional behavior assessment followed by a behavior modification program (Hubert, 1992; Hyman et al., 2020; Kazdin, 2013). If additional help to manage the behaviors is needed, psychotropic medications may be prescribed. Effective medication management is considered a standard of practice because behavioral problems hinder participation in therapeutic interventions, educational programs, and family life, leading to diminished socialization opportunities and decreased quality of life (Hyman et al., 2020; Myers & Johnson, 2007).

In addition to self- and other- injurious behavior, severe temper tantrums, irritability, and hyperactivity, sleep disturbances such as inability to fall and stay asleep have been extensively documented in children with ASD (Allik, Larsson, & Smedje, 2006; Gail-Williams, Sears, & Allard, 2004; Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008). Assessment of sleep disturbances usually starts with a medical history to rule out obstructive sleep apnea, gastro-esophageal reflux disease, current medications that affect sleep latency, or underlying conditions such as ADHD. Determining if the issue is related to disturbed sleep phase (e.g. waking up at 2 am thinking it is morning) is also part of the assessment. If there are no known underlying medical issues that are causing sleep disturbances, then behavioral therapy as well as

melatonin, an endogenous pineal hormone that regulates human circadian rhythm, is often recommended (Andersen et al., 2008; Malow et al., 2012). If melatonin is not effective, the next treatment options are usually psychotropic medications such as trazadone, diphenhydramine, or clonidine (Coury et al., 2009).

This study contributes to the literature that has identified racial and ethnic differences in certain aspects of ASD such as prevalence (Kogan et al., 2007), age of diagnosis (Mandell et al., 2002, 2009), and parental coping styles and interpretations of ASD symptomatology (Luong et al., 2009; Tek & Landa, 2012). Racial and ethnic healthcare disparities experienced by children with ASD and their families have been consistently documented in utilization and quality of healthcare (Parish, Magaña, Rose, Timberlake, & Swaine, 2012), access to family-centered care (Montes & Halterman, 2011), decisions regarding treatment and services (Bernier et al., 2010; Mandell & Novak, 2005), experiences of ASD diagnosis and treatment planning (Burkett et al., 2015); and parental attendance at support groups (Mandell & Saltzer, 2007). Children with ASD from Latino, Black, and other minority groups are less likely to receive subspecialty services in psychiatry and mental health treatment (Benevides, Carretta, & Lane, 2016; Broder-Fingert, Shui, Pulcini, Kurowski, & Perrin, 2013), which may contribute to disparities in psychotropic medication use.

Research findings on psychotropic medication use, however, are contradictory. In a study of medications use in 2 to 18 year-old children enrolled in the Autism Treatment Network (ATN) registry who had comorbid diagnoses of depression, bipolar disorder, attention deficit hyperactivity disorder, obsessive compulsive disorder, anxiety, behavioral sleep problems, and gastrointestinal problems, Coury et al. found that non-White and Latino children had a significantly lower use of psychotropic medication than White children (Coury et al., 2012). Alternatively, in a study of 33,565 commercially insured children with ASD enrolled in the

Interactive Autism Network (IAN) that did not correlate behavior challenges with psychopharmacological medication use, Latino and Asian children were *more* likely to receive psychotropic and polypharmacy prescriptions than White children (Spencer et al., 2013). In an earlier study, Rosenberg and colleagues (2010) analyzed IAN data for 5,181 children most of whom were between the ages of 6 and 11 years old and found no racial or ethnic differences in psychotropic medication use. These researchers did identify, however, differences in psychotropic medication use by age, type of ASD diagnosis, presence of intellectual disability or psychiatric condition, geographic region, and relative county wealth, all of which are external to clinical symptom presentation (Rosenberg et al., 2010). A more nuanced and culturally-sensitive understanding of differences in psychotropic medication use has a potential to clarify the contradictions in the literature, and to contribute to better care for children with ASD from racial and ethnic minority groups.

### **Conceptual Model**

Originating in medical sociology, Andersen's (1995) Behavioral Model of Healthcare use has been utilized extensively in public health research and has been especially useful in studies on ethnic and racial disparities in healthcare for children with ASD (Magaña et al., 2012). In this model, population characteristics are systematically accounted for so that patients' use of healthcare services (e.g. being prescribed a medication) is considered to be a function of predisposing factors (e.g. race or ethnicity, cultural beliefs about health and medicine), enabling factors (health insurance, socio-economic status and its proxy, parental college education), and need factors consisting of perceived need (e.g. the child's severity of behavioral symptoms as experienced by the parents) and evaluated need (e.g. the child's severity of behavioral symptoms

as evaluated by a healthcare professional).

The model is illustrated below:

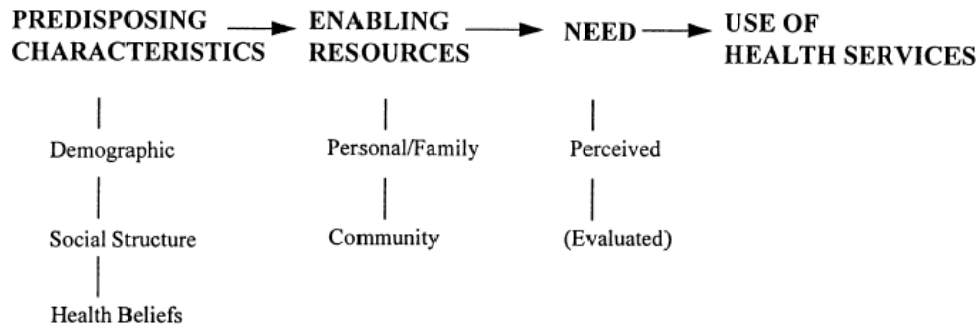


Figure 1. Andersen's Behavioral Model of Healthcare Use (Andersen, 1995)

Andersen's (1995) distinction between *perceived* need and *evaluated* need is especially useful because it allows for both culturally-shaped parental interpretations and beliefs regarding problem behaviors and medication use, and for the potential physician bias in identification of behavior and medication management. Data in the ATN registry allowed us to evaluate racial and ethnic differences in behavioral problems including sleep, and in medication use in relation to the 1) *predisposing factors* (race and ethnicity); 2) *enabling factors* (parental education, whether a parent had above high school-level education), and 3) *need factors* such as Behavioral Challenges, Total Problem Behaviors, Hyperactivity, Conduct Problems as measured by the Child Behavioral Checklist (CBCL, Achenbach, & Rescorla, 2001; Rescorla et al., 2007), and Sleep Disturbances as measured by the Child Sleep Habits Questionnaire (CSHQ, Owens, Spirito, & McGuinn, 2000).

Our two main research questions were whether race and ethnicity, the predisposing factors in the Andersen's (1995) model, were associated with differences in 1) the prevalence of Behavioral Challenges, Total Problem Behaviors, Hyperactivity, Conduct problems, and Sleep



Disturbances; and 2) the rates of medication use among children with ASD in our ATN sample. Because parental income, an enabling factor, constitutes the largest missing data category in the ATN registry, we substituted it with a more available proxy, parental education (Erola, Jalonen, & Lehti, 2016). Primary and secondary caregivers were grouped as those who had high school education or less, and those who had some college education or more.

## **Methods**

### **Participants**

The sample for this study was 2,576 children with ASD who were 6 to 18 years old between March 2008 and March 2016 when they were enrolled in the ATN registry (See Table 1). The children's data were included in our analyses if a) they had race, ethnicity and gender data available; b) they had a clinical diagnosis of an ASD based on the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition, Text Revision (APA, 2000); c) they were between 6 and 18 years of age; and d) their parents provided medication use information that was confirmed by an ATN clinician during enrollment.

The mean age was 9.6 years at enrollment. The race or ethnicity of the children were characterized by their parents as follows: 1,935 Non-Hispanic Whites, 255 Hispanics, 154 Blacks, 89 Asians, and 143 Non-Hispanic Other or Multiracial children. The racial and ethnic breakdown for this sample was 75% White, 9.9% Hispanic, 6% Black, 3.5 % Asian, and 5.6 % Multiracial; 84.7% (2182) of the sample was male. As presented in Table 2, White and Black children were older (mean (sd): 9.8 (2.9)) than Asian (9.2 (2.7)), Hispanic (9.1 (2.5)), and other/multiracial (9.0 (2.6)) children ( $p \leq 0.01$ ). Primary and secondary caregiver's education level was the lowest among Latino adults; 32% had  $\leq$ high school education compared with 16-19% among other groups ( $p \leq 0.01$ ). Hispanic (70%), Black (74%), and Asian (82%) children had higher rates of diagnosis

with Autistic Disorder compared to Asperger's Disorder ( $p \leq 0.01$ ) (DSM IV-TR, APA, 2000) than did White children (61%).

## Measures

**The Child Behavior Checklist (CBCL).** The CBCL is one of the most widely used, validated, cross-culturally tested parent-report clinical measure for children that identifies a wide range of emotional and behavioral challenges (Achenbach & Rescorla, 2001; Rescorla et al., 2007). It is known for its adequate reliability and construct validity (test-retest reliability (.89), inter-parent reliability (.65-.75), Cronbach's alpha values (.46-.93) (Achenbach, 1991). Most parents with average literacy level find the CBCL easy to complete, and most clinicians find it easy to score (Muratori et al., 2011). It is important to note that children whose parents are not fluent in both written and spoken English are not eligible to participate in the ATN registry, which contributes to a potentially more acculturated sub-set of ethnically diverse families (Soke et al., 2017). While the CBCL was not developed or normed to screen for ASD, it has been used occasionally to identify the appearance of autistic symptoms, e.g. by Rescorla (1988). Since the ATN registry began using the CBCL during its intake interview, the use of the CBCL for children with ASD has been on the rise (e.g. Bölte et al. 1999; Duarte et al. 2003; c.f. Muratori et al., 2011; Rescorla et al., 2019), in spite of concerns about its low specificity (Havdahl, von Tetzchner, Huerta, Lord, & Bishop, 2016).

The CBCL includes 8 empirically validated scales: Anxious / Depressed, Withdrawn / Depressed, Somatic Complaints, Social Problems, Thought Problems, Attention Problems, Rule-Breaking Behavior, and Aggressive Behavior. The scores on these scales are grouped into three scales: 1) Internalizing (Anxious/ Depressed, Withdrawn/Depressed, Somatic Complaints); 2)

Externalizing (Rule-Breaking Behavior, Aggressive Behavior), and 3) Total Problems scales (all items). The CBCL yields 6 Diagnostic and Statistical Manual of Mental Disorders (DSM)-oriented scales that were derived based on factor analysis: Affective Problems, Anxiety Problems, Somatic Problems, Attention Deficit/Hyperactivity (ADHD) Problems, Oppositional Defiant Problems, and Conduct Problems (Rescorla et al., 2007). Results from the CBCL are often used by clinicians to guide assessment and treatment, including medication use. To provide an overview of challenging behaviors, the CBCL scales were grouped and labeled in our study as follows: Total Problems Behaviors, Behavioral Challenges, Hyperactivity, and Conduct Problems (see Table 1).

**The Child Sleep Habits Questionnaire (CSHQ).** While the CBCL is sometimes used to assess sleep disturbance, it was not validated for this purpose. Thus we included the CSHQ, a 45-items validated survey completed by parents to assess sleep behavior in children ages 4-12 (Owens, Spirito, & McGuinn, 2000). The CSHQ domains include 8 domains: Bedtime Resistance, Sleep Onset Delay, Sleep Duration, Sleep Anxiety, Night Wakings, Parasomnias, Sleep-disordered Breathing, and Daytime Sleepiness (Owens, Spirito, & McGuinn, 2000). This survey has been used in research studies to examine sleep behaviors in children with and without ASD (Goldman, Richdale, Clemons, & Malow, 2012; Goodlin-Jones, Tang, Liu, & Anders, 2008; Malow et al., 2016). Psychometric properties ranged from 0.68 to 0.78 (internal consistency); 0.62 and 0.79 (test-retest reliability), 0.80 (sensitivity) and 0.72 (specificity) (Owens, Spirito, & McGuinn, 2000). A clinical cut-off score of  $\geq 41$  was used to indicate a sleep behavior disturbance (Owens, Spirito, & McGuinn, 2000; Malow et al., 2016).

**Medication Use.** Parents reported history of medication use for their children at the time of enrollment into the registry. This information was confirmed by ATN clinicians during a

clinical appointment, and entered into the registry data sheet. For this analysis, the medications were classified for each behavioral problem. The classification of medication use for behavioral challenges (i.e. Total Problem Behaviors medication use, Hyperactivity medication use, Conduct Problems medication use, and Sleep Disturbances medication use) included stimulants, atomoxetine, alpha agonists, atypical antipsychotic medications, melatonin, anticonvulsants, and antidepressants. Anticonvulsant medications were included in the analysis because certain anticonvulsant medications are used for behavioral management and mood stabilization. Medication use was dichotomized (use or not use) as a dependent variable. Table 1 provides a summary of terminological linkages of CBCL and CSHQ terms and the terms commonly used for clinical symptoms, as well as corresponding psycho-pharmacological classes and types of medications commonly prescribed for these clinical symptoms.

## **Procedures**

Across all its sites in the United States and Canada, the ATN currently provides healthcare services to more than 30,000 children and youth per year. Each site specializes in multi-disciplinary, coordinated behavioral and medical care for children, adolescents and young adults under 20 years of age. An ASD diagnosis is given after clinical evaluation based upon the ADOS or ADOS second edition (ADOS-2; Lord, Rutter, DiLavore, & Risi, 1999; Lord et al., 2012), the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition, Text Revision (APA, 2000) or Fifth Edition (APA, 2013), and clinician judgment (Kuhlthau et al., 2018). The ATN registry is approved by the institutional review board at each site's institution and the data are maintained by the Massachusetts General Hospital Biostatistics Center (Boston, MA).

Starting in December 2007, all families receiving care at one of the ATN sites were invited to join the ATN registry. To date, families of over 7,029 of children ages 2 -18 have

chosen to participate. ATN registry is limited to participants from sites located throughout the U.S. and two sites in Canada. To be enrolled in the ATN registry, families gave written informed consent, shared additional health information, and completed multiple standardized questionnaires. The ATN registry inclusion criteria include confirmation of an ASD diagnosis by a qualified, ATN-affiliated clinician. Parents also provided information regarding previous diagnoses, testing and treatments, and co-occurring health conditions and comorbid psychiatric diagnoses. This information reflected both parental understanding of their child's conditions, and previous practitioners' presumed perspectives and rationales for treatment. Parents provided a history of past and current medication use, which was confirmed during an interview with an ATN clinician. Additionally, behavioral and sleep questionnaires, including the Child Behavior Checklist (CBCL, Rescorla et al., 2007) and the Child Sleep Habits Questionnaire (CSHQ, Owens, et al., 2000) were collected and interpreted by an ATN clinician. CBCL and CSHQ scores were used to determine and characterize the behavioral challenges of children in the ATN registry. All data were then entered into the password protected, secure registry database by trained study coordinators at each site.

## **Analysis**

Summary statistics were generated for each racial and ethnic group characterized as White, Hispanic independently of race, Black, Asian and Multiracial. Only families with complete data were included in the summary table (Table 2) and initial bivariate analyses (i.e., cases with missing data on the specified outcomes were excluded, see Tables 3a and 4a). Thirteen % (333) of data was missing from the Total Problem Behaviors, 13.1% (338) from the Hyperactivity and Conduct problems, and 21.2% (547) from the Sleep Disturbances variable. Differences in the distribution of categorical variables among the ethnic and racial groups were

tested using two-sided chi-square tests of independence, and an ANOVA was used to assess group differences in mean ages. All covariates were chosen *a priori* based on prior literature about ASD disparities (Coury et al., 2012; Goldman, Richdale, Clemons, & Malow, 2012; Spencer et al., 2013) regardless of bivariate relationships.

The age range was the primary reason for limiting the number of subjects in this study. There were 6966 subjects enrolled in the Registry in total at the time of analysis. Of these 6966, 2801 (40%) were aged 6-18 (inclusive). The other 60% of the sample included 4129 (59%) subjects age 5 or younger, and 36 subjects (<1%) with no age data. Of those 2801, 2 (<1%) subjects were missing data on gender, 139 (5%) subjects were missing or declined to provide data on race and ethnicity, 77 (2.7%) were missing a specified DSM-IV ASD diagnosis, and 11 (<1%) were missing medication data. Combined, 225 subjects out of 2801 (8%) were not included in the analysis due to missing these types of data. This resulted in the final sample size of 2,576 subjects.

The percentage of subjects with any missing data varied from 33.7% (652) for White children to 57.3% (51) for Asian children. We used PROC MI to multiply the imputed data for missing observations based on race, ethnicity, age, gender, primary caregiver education, secondary caregiver education, ASD diagnosis, behavioral challenges and medication use, Total Problem behavior and medication use, hyperactivity problems and medication use, conduct problems and medication use, sleep disturbances and medication use, anxiety problems and medication use, and affective disorder problems and medication use.

Results from the 25 imputed datasets were combined using PROC MIANALYZE. Adjusted odds ratios (OR) ( i.e. the ratios of the odds of an event occurring in one group to the odds of it occurring in another group that is derived from logistic models, which allow for the

inclusion of additional variables to correct for heterogeneity) and 95% confidence intervals (CI) were obtained from separate multivariable logistic regression models assessing the potential relationship of each of the behavioral problems (see Table 3b) and medication use (see Table 4b), with race and ethnicity accounting for variables that were either significant in the bivariate analysis or conceptually appropriate to be included based upon literature review (Coury et al., 2012; Goldman et al., 2012; Spencer et al., 2013). They were age, gender, primary caregiver education, secondary caregiver education, and ASD diagnoses (DSM-IV-TR). The p-values for the combined from the multiply imputed datasets were computed using the methods described by Li, Meng, Raghunathan, and Rubin (1991). All analyses were conducted using SAS 9.4. (SAS Institute, 2015).

## **Results**

### **Behavioral Problems**

Our first research question was whether race and ethnicity, the predisposing factors in the Andersen's (1995) model, are associated with differences in the prevalence of Behavioral Challenges, Total Problem Behaviors, Hyperactivity, Conduct problems, and Sleep Disturbances among children and youth with ASD in our sample.

Distribution of clinically significant CBCL and CSHQ scores by race and ethnicity in the sample is presented in Table 3a. Results from the multivariable logistic regression on the multiply imputed datasets, accounting for age, gender, ASD diagnosis (Autistic Disorder, PDD-NOS, Asperger's Disorder), and parents' education level (high school or less vs. some college or more) are presented in Table 3b. There were no racial or ethnic differences in Behavioral Challenges, Conduct Problems, and Sleep Disturbances. There were, however, statistically significant findings for the lower odds of the Total Problem Behaviors in Black children; and

lower odds of Hyperactivity among Asian children. When racial and ethnic minority children in the sample were grouped together, they had significantly lower adjusted odds ratios for Total Problem Behaviors and Conduct Problems variables on the CBCL compared to Whites (see Table 3b).

### **Medication Use**

Our second research question was whether race and ethnicity, the predisposing factors in the Andersen's (1995) model, are associated with differences in the rates of medication use of children and youth with ASD in our sample.

Medication use was highest among White children for all behavioral variables except for Sleep Disturbances (see table 4a). Medication use ranged from 21.3% to 40.5% for Behavioral Challenges, 29.2% to 51.2% for Total Problem Behaviors, 12.4% to 33.7% for Hyperactivity, and 12.4% to 24.0% for Conduct Problems (all  $p \leq 0.01$ ).

Table 4b presents the adjusted odds ratios (OR) and 95% confidence intervals (CI) from multivariable logistic regressions, accounting for age, gender, education level of caregivers, and autism diagnosis to evaluate the association of reported medication use with race and ethnicity. Compared to White children, medication use for Behavioral Challenges, Total Problem Behaviors, Hyperactivity and Conduct Problems was the lowest among Hispanic children. Asian children also had lower odds of medication use for Behavioral Challenges, Total Problem Behaviors, and Hyperactivity; and had close to significantly lower odds in medication use for Conduct Problems. Black children had lower odds for medication use for Total Problem Behaviors only. As a group, minority children had lower odds of medication use for all of the categories except sleep disturbance ( $p$ -values all  $< 0.05$ ). Thus there were statistically significant, clinically meaningful racial and ethnic differences in the parent-reported medication use for all



behavioral variables except for Sleep Disturbances. Because Andersen's (1995) model allows to consider need factors in the use of health services such as prescription medications, in future research it would be important to evaluate the degree to which the racial and ethnic differences in perceived needs factors (parental perceptions and cultural beliefs) and the evaluated need factors (physician bias in prescribing less medications for minority groups compared to Whites) contribute to the pattern of racial and ethnic disparities in medication use for problem behaviors characteristic of ASD, with the exception of sleep disturbances.

## **Discussion**

Our analyses did not find an association between race and ethnicity and the prevalence of behavioral challenges, hyperactivity and sleep disturbances in multivariable logistic regression between each racial and ethnic group, however, when grouped together, children from racial and ethnic minority groups in the sample had significantly lower adjusted odds ratios for Total Problem Behaviors and Conduct Problems variables on the CBCL compared to White children

Inasmuch as there is no strong evidence that there are phenotypic differences in ASD presentation across racial and ethnic groups (e.g. Cucarro et al., 2007; Tek & Landa, 2012), our findings suggest that the CBCL as an instrument may fit White parents' descriptions of their children's challenging behaviors better than it does racial and ethnic minority parents'. Because CBCL scores are often used by healthcare providers as part of treatment decisions, the odds are higher that, compared with minority children, White children will receive more appropriate psychopharmacological support that is commensurate with their behavioral challenges. Moreover, because the CBCL was not normed for ASD and its complex heterogeneity, the introduction of cultural and linguistic diversity due to parents' and children's racial and ethnic backgrounds, as

reflected by preferences for interdependence vs. independence (Greenfield, 1994), may further account for differences in reported behavioral problems. This may place healthcare practitioners at a disadvantage, as the CBCL results may not be as reliable an instrument to identify and base treatment for behavior challenges in racially and ethnically diverse patients with ASD.

Our results are consistent with previous studies that have found racial and ethnic differences in the use of medication, with White children being significantly more likely to receive psychotropic medication when compared to other racial and ethnic groups (Coury et al., 2012; Spencer et al., 2013). There were, however, no differences in sleep challenges such as insomnia, nighttime awakening, and shorter sleep hours which may constitute one homogenous trait that seems to be more consistently identified and treated. Sleep disturbances associated with ASD are known to contribute to greater levels of maternal stress (Hoffman et al., 2008). As suggested by our findings, parents may characterize children's sleep disturbances similarly across racial and ethnic groups as sleep is more of a biological than cultural phenomenon. Sleep disturbances may be evaluated more equitably by health care professionals. This could account for the lack of differences in the use of medication for sleep disturbance across the different groups in our study.

### **Potential Factors contributing to Differences in Medication Use**

In spite of a growing interest in how population characteristics such as race, ethnicity, socio-economic status, and cultural beliefs may contribute to differences in several aspects of ASD (Horowitz et al., 2012, Mandell & Novak, 2005), it is mostly unknown whether variation in medication use is influenced by cultural differences in interpretation of behavioral challenges associated with ASD. Equally unknown is whether and how this variation may be engendered by differences in cultural attitudes towards psychotropic

medication use, in contrast to the use of over-the-counter medications or complementary and alternative medicine to decrease behavioral problems (e.g. Perrin et al., 2012). Addressing this gap in knowledge is important for at least two reasons: first, because of parents' and extended family members' central role in behavioral and psychotropic management of children' ASD symptomatology; and second, because racially and ethnically diverse families' cultural beliefs and preferred 'cultural scripts' (Greenfield, 1994) may differ in important ways from both the White middle class families and from the biomedical explanatory framework (Authors, 2017ab).

We interpret our findings through the lens of Andersen's (1995) Behavioral Model of Healthcare Use, to consider a range of interacting population characteristics that may affect racial and ethnic differences in medication use for children with ASD. Overall, drawing on our conceptual model, there are **predisposing factors** such as parents' cultural attitudes related to medication use; and **enabling factors** such as parents' education (a proxy for income) that may contribute to the differences in medication use. Additionally, the **need factors** such as the child's behavioral problems are likely to impact the odds of medication use.

**Predisposing Factors.** It is increasingly recognized in the autism literature that 'culture' matters in medical management of ASD, specifically, that parents' interpretations of challenging behaviors and their causes are often rooted in cultural beliefs (Horowitz et al., 2012; Reyes et al., 2018), making these behaviors, and behaviors associated with ASD in general, more or less distressing to the parents (Magaña & Smith, 2006; Tek & Landa, 2012). Moreover, the cultural explanatory frameworks that parents use to makes sense of these behaviors may be more or less consistent with biomedicine, which may facilitate or hinder locating the cause of a problematic

behavior in the clinical diagnosis rather than in the child's personhood (Bussing et al., 1998).

Increasingly, the research literature that focuses on cultural aspects of ASD suggests that cultural values linked to *interdependence* (e.g. the Latino value of 'familism') will generate a different interpretation of challenging behavior than those linked to Euro-American cultural preference for independence and individual responsibility (Greenfield et al., 2003). These cultural interpretations may be more or less consistent with the uses of psychotropic interventions rather than with alternative 'folk' medicine (Mandell & Novak, 2005; Levy et al., 2003).

Cultural differences in communicative norms and practices, such as deference to physicians' authority, may also influence diagnostic decisions and medication management among racial and ethnic minority families of children with ASD. In a study of a predominantly upper and upper-middle class, racially and ethnically diverse sample, Tek and Landa (2012) proposed that even affluent Latino and Asian parents' communication style may be characterized by more acceptance and less questioning of clinicians' judgment, which may disadvantage them in receiving adequate information about their children's diagnosis and treatment recommendations. Furthermore, research has identified factors such as cultural perceptions of health and the use of alternative medicine as contributing to the disparities in access to care observed in the Asian community (Augsberger et al., 2015; Jegatheesan, 2009; Mandell et al., 2008; Oswald, & Sonenklar, 2007; Son, Parish, & Igdalsky, 2017; Yu et al., 2010).

**Enabling Factors.** Parents' income, an enabling factor in the Andersen's (1995) model, is important because families with low socio-economic status (SES) are less likely to have consistent primary care (Lin, Stella, & Harwood, 2012; Liptak et al., 2008; Shattuck et al., 2009) and may be less likely to receive comprehensive medical services, including behavioral

assessment and medication management (Magaña et al., 2013). The main enabling factor of interest in our study, however, was parents' education rather than parents' income because the latter was the largest missing data category in the ATN registry. To address this problem we substituted it with a more available proxy, parental education (Erola, Jalonen, & Lehti, 2016) . Primary and secondary caregivers were grouped as those who had high school education or less, and those who had some college education or more. Latino parents in our study reported the lowest level of primary and secondary caregiver's education: 32% with not more than high school education compared with 16-19% parents from the other groups ( $p \leq 0.01$ ). As was discussed in the Results section, while the Hispanic children in the sample did not differ from children in the other groups on behavioral problems measured by the CBCL or on sleep disturbances measured by the CSHQ, they had the lowest medication use for Behavioral Challenges, Total Problem Behaviors, Hyperactivity and Conduct Problems compared to White children. In future studies, such linkages should be explored more systematically. Moreover, enabling factors such as acculturation and English-language proficiency should also be examined as they are likely to impact medication use of children with ASD growing up in minority families. Such studies, however, are currently beyond the scope of the ATN data registry because parents must be fluent in written and spoken English in order for their children to be eligible to participate, which contributes to a potentially more acculturated sub-set of ethnically diverse families (Soke et al., 2017).

**The Needs Factors.** While we could not directly evaluate whether there were racial and ethnic differences in **the need factors** for medication use associated with Behavioral Challenges, Total Problem Behaviors, Hyperactivity, Conduct problems, and Sleep Disturbances, we were intrigued by ways in which the 'perceived' and the 'evaluated' need factors for medication use, as

conceptualized in the Andersen's (1995) model, become merged in the ATN data. Specifically, we were aware that during an ATN intake interview parent-reported medication use may reflect both the evaluated (physician-based) and the perceived (parental beliefs-based) need. Similarly, parent reported CBCL measures may reflect perceived need factors however filtered, and potentially distorted, through the conceptual framework of the instrument.

### **Implications for Practice**

Our results have implications for clinical practice as they reinforce the need for clinical tools that allow the healthcare provider to correctly identify and treat behavioral challenges. Frequent surveillance of behavioral challenges in children with ASD throughout childhood and adolescence is a respectable goal, however, without sensitive and culturally appropriate instruments, care may be compromised.

The differences in the medication use among racial and ethnic groups call for additional efforts to enhance awareness and develop training related to the identification and medication treatment of behavioral challenges for minority pediatric populations with ASD. The use of psychopharmacological approaches for such problems should be an outcome of shared decision-making that involves health care professionals and parents, and takes into consideration the parents' concerns, communication styles, and cultural beliefs. Because shared decision-making is generally low in routine developmental-behavioral pediatrics visits (Anixt, Meinen-Derr, Estridge, Smith, & Brinkman, 2018), parents' cultural beliefs and attitudes towards medication use often remain undiscussed (Daley, 2004; Daley & Sigman, 2002; Mandell & Novak, 2005; Stevens et al., 2009; Tek & Landa, 2013). The lack of shared decision-making in a cross-cultural context might increase reliance on the use of survey tools, making it especially important that such instruments are designed to better elicit behavior symptoms from parents from diverse cultural

backgrounds to form a basis for treatment intervention. As on-line surveys and mobile phone apps become widespread in healthcare, both psychometric and cultural sensitivity of these tools should be a priority.

### **Limitations**

Our study has several limitations. The generalizability of our results is limited because recruitment for ATN does not involve random sampling. The ATN data collection process is also a limitation of our study. There are information gaps regarding families' socio-demographic characteristics, especially SES and health insurance, which are both enabling factors in Andersen's (1995) conceptual model. As Coury et al. (2012) pointed out, there is minimal information on the ATN families' socio-economic status, and a disproportionately large percentage of White families in the registry, a group that on average has higher SES than racial/ethnic minority families. This hinders the study of demographic and cultural differences in diagnosis and medication use. Both cultural differences and disparities in care warrant further attention, however, because they affect both healthcare seeking and receiving behaviors (Coury et al., 2012, p. S75).

Relatively small sample sizes of the racial and ethnic group with different rates of each ASD diagnosis is also a limitation. Thus the number of cases in an ethnic group may have been quite small, such that only large differences could be detected. Missing data, as discussed above, is also a limitation. In the age group of interest, less than 1% subjects were missing data on gender, 139 (5%) subjects were missing or declined to provide data on race and ethnicity, 77 (2.7%) were missing a specified DSM-IV ASD diagnosis, and 11 (<1%) were missing medication data. Combined, 225 subjects out of 2801 (8%) were not included in the analysis due to missing these types of data.

Finally, because data were obtained at the time of enrollment into the ATN registry and no information was available about the chronology of behavioral problems on-set and start of medication use, it is impossible to consider a cause-and-effect relationship between the two. CBCL scores were used to determine whether behavioral challenges were present by choosing clinically significant scores; however, we were not able to verify whether the children in the sample had a confirmed behavioral diagnosis or if the CBCL results were used in treatment decisions which may provide a limited understanding of co-occurring behavioral diagnosis and medication use in the sample.

## **Summary**

Our findings identify racial and ethnic differences in medication use for all behavioral problems except sleep disturbances. We used Andersen's (1995) Behavioral Model of Healthcare use as a conceptual and theoretical framework that aimed to account for a range of population characteristics that constitute predisposing, enabling, and needs factors in behavioral problems and medication use. Future studies should evaluate more extensively the correlations between problem behaviors and medication use, and estimate whether there are racial and ethnic differences in these correlations. Our approach is anticipated to enhance understanding of parent reported behavioral challenges among racially diverse children with ASD that may ultimately impact psychotropic interventions for this pediatric population.



## **Bibliography**

- Achenbach, T. M. (1991). Manual for the Child Behavior Checklist/4-18 and 1991 profile. Burlington, VT: University of Vermont. *Research Center for Children, Youth, and Families*.
- Achenbach, T. M., & Rescorla, L. A. (2001). Manual for the ASEBA School–Age Forms & Profiles. Burlington, VT: University of Vermont. *Research Center for Children, Youth, and Families*.
- Allik, H., Larsson, J. O., & Smedje, H. (2006). Insomnia in school-age children with Asperger syndrome or high-functioning autism. *BMC Psychiatry*, 6(1), 18.
- American Psychiatric Association. (2000). Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR (text revision). Washington, DC: American Psychological Association.
- American Psychiatric Association. (2013). Diagnostic and Statistical Manual of Mental Disorders (5th edn.) (DSM-5). Washington, DC: American Psychological Association.
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter?. *Journal of health and social behavior*, 36 (1), 1-10.
- Andersen, I. M., Kaczmarek, J., McGrew, S. G., & Malow, B. A. (2008). Melatonin for insomnia in children with autism spectrum disorders. *Journal of child neurology*, 23(5), 482-485.
- Authors (2017a). *Disability & Society*.
- Authors (2017b). *OTJR: Occupation, Participation and Health*.
- Anixt, J. S., Meinzen-Derr, J., Estridge, H., Smith, L., & Brinkman, W. B. (2018). Characteristics of treatment decisions to address challenging behaviors in children with autism spectrum disorder. *Journal of Developmental and Behavioral Pediatrics*, 39(4), 282-291.

- Augsberger, A., Yeung, A., Dougher, M., & Hahm, H. C. (2015). Factors influencing the underutilization of mental health services among Asian American women with a history of depression and suicide. *BMC Health Services Research*, *15*(1), 542.
- Bauminger, N., Solomon, M., & Rogers, S. J. (2010). Externalizing and internalizing behaviors in ASD. *Autism Research*, *3*(3), 101-112.
- Benevides, T. W., Carretta, H. J., & Lane, S. J. (2016). Unmet need for therapy among children with autism spectrum disorder: Results from the 2005–2006 and 2009–2010 National Survey of Children with Special Health Care Needs. *Maternal and Child Health Journal*, *20*(4), 878-888
- Bernier R, Mao A, Yen J. (2010). Psychopathology, families, and culture: Autism. *Child and Adolescent Psychiatric Clinics of North America*, *19*:855–867.
- Bölte, S., Dickhut, H., & Poustka, F. (1999). Patterns of parent-reported problems indicative in autism. *Psychopathology*, *32*(2), 93-97.
- Broder-Fingert, S., Shui, A., Pulcini, C. D., Kurowski, D., & Perrin, J. M. (2013). Racial and ethnic differences in subspecialty service use by children with autism. *Pediatrics*, *132*(1), 94-100.
- Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of Autism and Developmental Disorders*, *45*(10), 3244-3254.
- Bussing R, Schoenberg N, Perwien A. 1998. Knowledge and information about ADHD: Evidence of cultural differences among African American and white parents. *Soc Sci Med* *46*:919 –928.
- Coury, D. L., Anagnostou, E., Manning-Courtney, P., Reynolds, A., Cole, L., McCoy, R., ... & Perrin, J. M. (2012). Use of psychotropic medication in children and adolescents with

- autism spectrum disorders. *Pediatrics*, 130 (Supplement 2), S69-S76.
- Coury, D., Jones, N. E., Klatka, K., Winklosky, B., & Perrin, J. M. (2009). Healthcare for children with autism: the Autism Treatment Network. *Current opinion in pediatrics*, 21(6), 828-832.
- Cuccaro, M. L., Brinkley, J., Abramson, R. K., Hall, A., Wright, H. H., Hussman, J. P., ... & Pericak-Vance, M. A. (2007). Autism in African American Families: Clinical-phenotypic findings. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, 144(8), 1022-1026.
- Daley, T. C. (2004). From symptom recognition to diagnosis: children with autism in urban India. *Social Science & Medicine*, 58(7), 1323-1335.
- Daley, T. C., & Sigman, M. D. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *Journal of Autism and Developmental Disorders*, 32(1), 13-23.
- Duarte C.S., Bordin I.A.S., De Oliveira A., Bird H. (2003). The CBCL and the identification of children with autism and related conditions in Brazil: pilot findings. *Journal of Autism and Developmental Disorders* 33, 703–707
- Erola, J., Jalonen, S., & Lehti, H. (2016). Parental education, class and income over early life course and children's achievement. *Research in Social Stratification and Mobility*, 44, 33-43.
- Frazier, T. W., Shattuck, P. T., Narendorf, S. C., Cooper, B. P., Wagner, M., & Spitznagel, E. L. (2011). Prevalence and correlates of psychotropic medication use in adolescents with an autism spectrum disorder with and without caregiver-reported attention-deficit/hyperactivity disorder. *Journal of Child and Adolescent*

- Psychopharmacology*, 21(6), 571-579.
- Gail-Williams, P., Sears, L. L., Allard, A. (2004). Sleep problems in children with autism. *Journal of Sleep Research*, 13(3), 265-268.
- Goldman, S. E., Richdale, A. L., Clemons, T., & Malow, B. A. (2012). Parental sleep concerns in autism spectrum disorders: Variations from childhood to adolescence. *Journal of Autism and Developmental Disorders*, 42(4), 531-538.
- Goodlin-Jones, B. L., Tang, K., Liu, J., & Anders, T. F. (2008). Sleep patterns in preschool-age children with autism, developmental delay, and typical development. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(8), 930-938.
- Goodlin, T., Chavez, B., Olfson, M., & Crystal, S. (2009). National patterns in the outpatient pharmacological management of children and adolescents with autism spectrum disorder. *Journal of Clinical Psychopharmacology*, 29(3), 307-310.
- Goyal, M. K., Kuppermann, N., Cleary, S. D., Teach, S. J., & Chamberlain, J. M. (2015). Racial Disparities in Pain Management of Children With Appendicitis in Emergency Departments. *JAMA Pediatrics*, 169(11), 996-1002.
- Greenfield, P. M., Keller, H., Fuligni, A., & Maynard, A. (2003). Cultural pathways through universal development. *Annual review of psychology*, 54(1), 461-490.
- Greenfield, P. M. (1994). Independence and interdependence as developmental scripts: Implications for theory, research, and practice. *Cross-cultural roots of minority child development*, 1-37.
- Havdahl, K.A., von Tetzchner, S., Huerta, M., Lord, C., & Bishop, S.L. (2016). Utility of the Child Behavior Checklist as a screener for autism spectrum disorder. *Autism Research*, 9(1), 33-42.

- Horowitz, M., Matson, J. L., Rieske, R. D., Kozlowski, A. M., & Sipes, M. (2011). The relationship between race and challenging behaviours in infants and toddlers with autistic disorder and pervasive developmental disorder–not otherwise specified. *Developmental Neurorehabilitation, 14*(4), 208-214.
- Hoffman, C. D., Sweeney, D. P., Lopez-Wagner, M. C., Hodge, D., Nam, C. Y., & Botts, B. H. (2008). Children with autism: Sleep problems and mothers' stress. *Focus on Autism and Other Developmental Disabilities, 23*(3), 155-165.
- Hubert, J. (1992). *Too Many Drugs, Too Little Care: Parents' Perceptions of the Administration and Side-effects of Drugs Prescribed for Young People with Severe Learning Difficulties*. London, U.K.: Values into Action.
- Hyman, S.L., Levy, S. E., Myers, S. M., & Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics (2020). Identification, Evaluation, and Management of Children with Autism Spectrum Disorder, *Pediatrics, 145*(1): e20193447.
- Jegatheesan, B. (2009). Cross-cultural issues in parent-professional interactions: A qualitative study of perceptions of Asian American mothers of children with developmental disabilities. *Research and Practice for Persons with Severe Disabilities, 34*(3-4), 123-136.
- Kazdin, A. E. (2012). *Behavior modification in applied settings*. Seventh Edition. Long Grove, IL: Waveland Press.
- Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., ... & van Dyck, P. C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics, 124*(5), 1395-1403.

- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*, *122*(6), e1149-e1158.
- Kogan MD, Blumberg SJ, Schieve LA, Boyle CA, Perrin JM, Ghandour RM, Singh GK, Strickland BB, Trevathan E, van Dyck PC. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*, *124*:1395–1403.
- Kuhlthau, K. A., Bailey, L. C., Baer, B. L., Coury, D. L., Law, J. K., Murray, D. S., ... & Lipkin, P. H. (2018). Large Databases for pediatric research on children with autism spectrum disorder. *Journal of Developmental and Behavioral Pediatrics*, *39*(2), 168-176.
- Krakowiak, P., Goodlin-Jones, B., Hertz-Picciotto, I., Croen, L. A., & Hansen, R. L. (2008). Sleep problems in children with autism spectrum disorders, developmental delays, and typical development: a population-based study. *Journal of Sleep Research*, *17*(2), 197-206.
- Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J., ... & Lainhart, J. E. (2006). Comorbid psychiatric disorders in children with autism: interview development and rates of disorders. *Journal of Autism and Developmental Disorders*, *36*(7), 849-861.
- Li, K. H., Meng, X. L., Raghunathan, T. E., & Rubin, D. B. (1991). Significance levels from repeated p-values with multiply-imputed data. *Statistica Sinica*, 65-92.
- Lin, S. C., Stella, M. Y., & Harwood, R. L. (2012). Autism spectrum disorders and developmental disabilities in children from immigrant families in the United

- States. *Pediatrics*, 130 (Supplement 2), S191-S197.
- Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: Data from the National Survey of Children's Health. *Journal of Developmental & Behavioral Pediatrics*, 29(3), 152-160.
- Logan, S. L., Nicholas, J. S., Carpenter, L. A., King, L. B., Garrett-Mayer, E., & Charles, J. M. (2012). High prescription drug use and associated costs among Medicaid-eligible children with autism spectrum disorders identified by a population-based surveillance network. *Annals of Epidemiology*, 22(1), 1-8.
- Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (1999). Autism diagnostic observation schedule manual. *Los Angeles: Western Psychological Services*.
- Lord, C., Rutter, M., DiLavore, P., Risi, S., Gotham, K., & Bishop, S. (2012). Autism Diagnostic Observation Schedule Second Edition (ADOS-2) Manual (Part 1): Modules 1–4. *Torrance, CA: Western Psychological Services.*
- Luong J, Yoder MK, Canham D. Southeast Asian parents raising a child with autism: A qualitative investigation of coping styles. *The Journal of School Nursing* 2009; 25: 222–229.
- Magaña, S., Lopez, K., Aguinaga, A., & Morton, H. (2013). Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities*, 51(3), 141-153.
- Magaña, S., Parish, S. L., Rose, R. A., Timberlake, M., & Swaine, J. G. (2012). Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual and developmental disabilities*, 50(4), 287-299.

- Malow, B. A., Marzec, M. L., McGrew, S. G., Wang, L., Henderson, L. M., & Stone, W. L. (2006). Characterizing sleep in children with autism spectrum disorders: a multidimensional approach. *Sleep, 29*(12), 1563-1571.
- Magaña, S., & Smith, M. J. (2006). Psychological distress and well-being of Latina and non-Latina White mothers of youth and adults with an autism spectrum disorder: cultural attitudes towards coresidence status. *American Journal of Orthopsychiatry, 76*(3), 346-357.
- Malow, B., Adkins, K. W., McGrew, S. G., Wang, L., Goldman, S. E., Fawkes, D., & Burnette, C. (2012). Melatonin for sleep in children with autism: a controlled trial examining dose, tolerability, and outcomes. *Journal of autism and developmental disorders, 42*(8), 1729-1737.
- Malow, B. A., Katz, T., Reynolds, A. M., Shui, A., Carno, M., Connolly, H. V., ... & Bennett, A. E. (2016). Sleep difficulties and medications in children with autism spectrum disorders: A registry study. *Pediatrics, 137* (Supplement 2), S98-S104.
- Mandell DS, Listerud J, Levy SE, Pinto-Martin JA. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*:1447-1453.
- Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37*(9), 1795-1802.
- Mandell, D. S., Morales, K. H., Marcus, S. C., Stahmer, A. C., Doshi, J., & Polsky, D. E. (2008). Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. *Pediatrics, 121*(3), e441-e448.



- Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*(6), 1480-1486.
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuseppi, C., Durkin, M. S., ... & Shattuck, P. T. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health, 99*(3), 493-498.
- Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11*(2), 110-115.
- Mandell, D. S., & Salzer, M. S. (2007). Who joins support groups among parents of children with autism?. *Autism, 11*(2), 111-122.
- Matson, J. L., & Cervantes, P. E. (2014). Assessing aggression in persons with autism spectrum disorders: An overview. *Research in developmental disabilities, 35*(12), 3269-3275.
- McQuaid, E. L., & Landier, W. (2018). Cultural issues in medication adherence: Disparities and directions. *Journal of General Internal Medicine, 33*(2), 200-206.
- Montes, G., & Halterman, J. S. (2011). White-Black disparities in family-centered care among children with autism in the United States: Evidence from the NS-CSHCN 2005–2006. *Academic Pediatrics, 11*(4), 297-304.
- Myers, S. M., & Johnson, C. P. (2007). Management of children with autism spectrum disorders. *Pediatrics, 120*(5), 1162-1182.
- Oswald, D. P., & Sonenklar, N. A. (2007). Medication use among children with autism spectrum disorders. *Journal of Child and Adolescent Psychopharmacology, 17*(3), 348-355.
- Owens, J. A., Spirito, A., & McGuinn, M. (2000). The Children's Sleep Habits Questionnaire

- (CSHQ): Psychometric properties of a survey instrument for school-aged children. *SLEEP*, 23(8), 1043-1052.
- Parish, S., Magaña, S., Rose, R., Timberlake, M., & Swaine, J. G. (2012). Health care of Latino children with autism and other developmental disabilities: Quality of provider interaction mediates utilization. *American Journal on Intellectual and Developmental Disabilities*, 117(4), 304-315.
- Perrin, J. M., Coury, D. L., Hyman, S. L., Cole, L., Reynolds, A. M., & Clemons, T. (2012). Complementary and alternative medicine use in a large pediatric autism sample. *Pediatrics*, 130(Supplement 2), S77-S82.
- Rescorla, L., Achenbach, T., Ivanova, M. Y., Dumenci, L., Almquist, F., Bilenberg, N., ... & Erol, N. (2007). Behavioral and emotional problems reported by parents of children ages 6 to 16 in 31 societies. *Journal of Emotional and Behavioral Disorders*, 15(3), 130-142.
- Rescorla, L. A., Winder-Patel, B. M., Paterson, S. J., Pandey, J., Wolff, J. J., Schultz, R. T., & Piven, J. (2019). Autism spectrum disorder screening with the CBCL/1½–5: Findings for young children at high risk for autism spectrum disorder. *Autism*, 23(1), 29-38.
- Reyes, N. M., Lindly, O. J., Chavez, A. E., Folan, A., Macias, K., Smith, K. A., ... & Zuckerman, K. (2018). Maternal beliefs about autism: A link between intervention services and autism severity in White and Latino mothers. *Research in Autism Spectrum Disorders*, 51, 38-48.
- Rosenberg, R. E., Mandell, D. S., Farmer, J. E., Law, J. K., Marvin, A. R., & Law, P. A. (2010). Psychotropic medication use among children with autism spectrum disorders enrolled in a national registry, 2007–2008. *Journal of Autism and Developmental Disorders*, 40(3), 342-351.

- SAS Institute. (2015). *Base SAS 9.4 procedures guide*. SAS Institute.
- Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D. S., Wiggins, L., ... & Baio, J. (2009). Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of the American Academy of Child and Adolescent Psychiatry*, *48*(5), 474-483.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, *47*(8), 921-929.
- Son, E., Parish, S. L., & Igdalsky, L. (2017). Disparities in health care quality among Asian children with special health care needs. *Health & Social Work*, *42*(2), 95-102.
- Soke, G. N., Rosenberg, S. A., Hamman, R. F., Fingerlin, T., Rosenberg, C. R., Carpenter, L., ... & Reynolds, A. (2017). Factors associated with self-injurious behaviors in children with autism spectrum disorder: findings from two large national samples. *Journal of autism and developmental disorders*, *47*(2), 285-296.
- Spencer, D., Marshall, J., Post, B., Kulakodlu, M., Newschaffer, C., Dennen, T., ... & Jain, A. (2013). Psychotropic medication use and polypharmacy in children with autism spectrum disorders. *Pediatrics*, *132*(5), 833-840.
- Stevens, J., Wang, W., Fan, L., Edwards, M. C., Campo, J. V., & Gardner, W. (2009). Parental attitudes toward children's use of antidepressants and psychotherapy. *Journal of Child and Adolescent Psychopharmacology*, *19*(3), 289-296.
- Tek, S., & Landa, R. J. (2012). Differences in autism symptoms between minority and non-minority toddlers. *Journal of Autism and Developmental Disorders*, *42*(9), 1967-1973.
- Yu, S. M., Huang, Z. J., & Singh, G. K. (2010). Health status and health services access and

utilization among Chinese, Filipino, Japanese, Korean, South Asian, and Vietnamese children in California. *American Journal of Public Health*, 100(5), 823-830.

Zablotsky, B., Pringle, B. A., Colpe, L. J., Kogan, M. D., Rice, C., & Blumberg, S. J. (2015). Service and treatment use among children diagnosed with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics*, 36(2), 98.

Table 1: Terminology of CBCL and CSHQ scales / domains, terms for clinical symptoms, and corresponding psycho-pharmacological medications

CBCL or CSHQ Scale / Domain	Description of Scale / Domain	Clinical label	Medication groups	Type of medication used for each category
Externalizing Behaviors	Rule-Breaking and Aggressive Behaviors	Behavioral Challenges	ADHD medications, Alpha Agonists, Anti-convulsant, Atypical antipsychotics	<u>ADHD medications:</u> Mixed Amphetamine Salts; Lisdexamphetamine; Methylphenidate, Dexmethylphenidate, Atomoxetine <u>Alpha Agonists:</u> Clonidine, Guanfacine <u>Anti-convulsant medications:</u> Oxcarbazepine, Valproic acid, Lamotrigine <u>Atypical Antipsychotics:</u> Aripiprazole, Risperidone
Total Problem Behaviors	Anxious/Depressed, Withdrawn/Depressed, Somatic Complaints, Rule-Breaking and Aggressive Behavior	Total Problem Behaviors	ADHD medications, Alpha Agonists, Anti-convulsant medications, Atypical antipsychotics, SSRI Endogenous pineal hormone	All Externalizing Behavior medications plus Selective serotonin re-uptake inhibitors (SSRI): Citalopram, Escitalopram, Fluoxetine, Sertraline  Melatonin
Attention Deficit Hyperactivity Disorder	Inattention, impulsivity, hyperactivity	Hyperactivity	ADHD medications, Alpha Agonists	ADHD medications: Mixed Amphetamine Salts; Lisdexamphetamine, Methylphenidate, Dexmethylphenidate, Atomoxetine Alpha Agonists: Clonidine, Guanfacine
Conduct Problems	Disruptive, Oppositional, and Conduct issues		Alpha Agonists, Antipsychotics	Alpha Agonists: Clonidine, Guanfacine  Atypical Antipsychotics: Aripiprazole, Risperidone
Sleep Disturbances	Bedtime behavior, sleep onset; sleep duration; sleep anxiety; behavior occurring during sleep; sleep disordered breathing; parasomnias		Melatonin, Anti-convulsant medications	Melatonin  Anti-convulsant medications: Oxcarbazepine, Valproic acid, Lamotrigine

**Table 2: Distribution of Gender, ASD Diagnoses, and Caregiver Education by Race and Ethnicity Among (N=2,576) Children 6-18 years of Age in the ATN Data**

	Race/Ethnicity					P-value <sup>a</sup>
	White (n=1935)	Latino (n=255)	Black (n=154)	Asian (n=89)	Non-Hispanic Other/ Multiracial (n=143)	
<b>Age in years</b>	9.8 (2.9)	9.1 (2.5)	9.8 (2.9)	9.2 (2.7)	9.0 (2.6)	<0.01
	mean (SD)					
	% (n)					P-value <sup>b</sup>
<b>Gender</b>						0.18
Female	14.6 (282)	14.9 (38)	18.2 (28)	22.5 (20)	18.2 (26)	
Male	85.4 (1653)	85.1 (217)	81.8 (126)	77.5 (69)	81.8 (117)	
<b>DSM-IV TR Autism Diagnosis</b>						<0.01 <sup>*</sup>
Asperger's Syndrome	18.2 (353)	7.5 (19)	6.5 (10)	7.9 (7)	14.0 (20)	
Autistic Disorder	61.2 (1184)	69.8 (178)	74.0 (114)	82.0 (73)	63.6 (91)	
PDD NOS	20.6 (398)	22.7 (58)	19.5 (30)	10.1 (9)	22.4 (32)	
<b>Primary caregiver education level<sup>c</sup></b>						<0.01 <sup>*</sup>
High School or less	18.0 (325)	31.9 (73)	18.7 (26)	15.9 (13)	18.5 (25)	
Some college	33.7 (609)	30.6 (70)	46.0 (64)	15.9 (13)	40.0 (54)	
Bachelor's Degree	28.6 (517)	24.5 (56)	23.0 (32)	37.8 (31)	23.0 (31)	
Postgraduate Degree	19.7 (355)	13.1 (30)	12.2 (17)	30.5 (25)	18.5 (25)	
<b>Second caregiver education level<sup>c</sup></b>						<0.01 <sup>*</sup>
High School	23.3 (395)	42.9 (84)	42.5 (45)	13.2 (10)	28.6 (34)	
Some college	27.7 (470)	23.5 (46)	26.4 (28)	17.1 (13)	32.8 (39)	
Bachelor's Degree	28.6 (484)	21.4 (42)	21.7 (23)	31.6 (24)	22.7 (27)	
Postgraduate Degree	20.4 (345)	12.2 (24)	9.4 (10)	38.2 (29)	16.0 (19)	

<sup>a</sup> ANOVA

<sup>b</sup> X<sup>2</sup> test of independence

<sup>c</sup> Do not total 100% due to missing value.: Primary caregiver education missing 7.2% (185) of data.; and Secondary caregiver education missing 15.0% (385) of data.

\*Statistically significant p<0.05

**Table 3a: Distribution of Clinically Significant CBCL and CSHQ Scores by Race and Ethnicity Among (N=2,576) Children 6-18 years of Age in the ATN Data**

Variables	Race/Ethnicity					P value <sup>a</sup>
	White (n=1935)	Latino (n=255)	Black (n=154)	Asian (n=89)	Multiracial (n=143)	
	% (n <sup>b</sup> )					
Behavioral Challenges						
Yes	34.8 (598)	34.5 (70)	28.8 (38)	29.4 (20)	45.1 (55)	0.07
Total Target Behaviors						
Yes	62.0 (1065)	61.1 (124)	46.2 (61)	52.9 (36)	67.2 (82)	<0.01*
Hyperactivity						
Yes	27.0 (463)	26.1 (53)	23.7 (31)	13.2 (9)	33.6 (41)	0.04*
Conduct Problems						
Yes	14.2 (244)	13.8 (28)	9.2 (12)	5.9 (4)	21.3 (26)	0.02*
Sleep Disturbances						
Yes	67.4 (1044)	72.3 (136)	61.2 (74)	74.5 (41)	69.6 (80)	0.23

<sup>a</sup> X<sup>2</sup> test of independence

<sup>b</sup> Do not total 100% due to missing values: Behavioral challenges and Total Target Behaviors missing 13.0% (333) of data; Hyperactivity and Conduct problems missing 13.1% (338) of data; Sleep Problems missing 21.2% (547) of data.

\*Statistically significant p<0.05

**Table 3b: Adjusted Odds Ratios of Race & Ethnicity and Behavioral Problems \***

Variables	Race/Ethnicity compared to Non-Hispanic White				P value
	Hispanic	Black	Asian	Multiracial	
	<b>Odd Ratio Estimates and 95% Confidence Limits</b>				
Behavioral Challenges	0.84 (0.61, 1.15)	0.71 (0.48, 1.05)	0.86 (0.50, 1.48)	1.45 (1.00, 2.11)	0.06
Total Problem Behaviors	0.86 (0.63, 1.18)	0.51 (0.36, 0.72)	0.80 (0.49, 1.31)	1.23 (0.83, 1.82)	0.01*
Hyperactivity	0.82 (0.59, 1.15)	0.75 (0.49, 1.14)	0.49 (0.25, 0.95)	1.28 (0.87, 1.88)	0.07
Conduct Problems	0.75 (0.48, 1.16)	0.55 (0.29, 1.03)	0.42 (0.15, 1.17)	1.48 (0.94, 2.34)	0.02*
Sleep Disturbances	1.07 (0.77, 1.49)	0.70 (0.46, 1.05)	1.75 (0.90, 3.40)	0.99 (0.66, 1.48)	0.28

\* Results obtained from multivariable logistic regression models that included age (continuous), gender (male/female), primary caregiver education (High School or less, some college, bachelor degree, post-graduate degree), secondary caregiver education (High School or less, some college, college degree, post-graduate degree), and autism diagnosis (Autism, Asperger's, PDD/NOS) as covariates. Results summarized from multiply imputing missing data 25 times.

\*Statistically significant  $p < 0.05$



**Table 4a: Distribution of Rates of Medication Use by Race and Ethnicity Among (N=2,576) Children 6-18 years of Age in the ATN Data**

Variables	Race/Ethnicity					P-value
	White (n=1935)	Latino (n=255)	Black (n=154)	Asian (n=89)	Multiracial (n=143)	
	% (n)					
Behavioral Challenges Medication						<0.01*
Yes	40.5 (783)	26.7 (68)	34.4 (53)	21.3 (19)	37.1 (53)	
Total Target Behaviors Medication						0.01*
Yes	51.2 (990)	34.1 (87)	40.9 (63)	29.2 (26)	45.5 (65)	
Hyperactivity Medication						<0.01*
Yes	33.7 (652)	21.6 (55)	26.6 (41)	12.4 (11)	26.6 (38)	
Conduct Problems Medication						0.01*
Yes	20.8 (402)	13.3 (34)	24.0 (37)	12.4 (11)	21.7 (31)	
Sleep Disturbances Medication						0.12
Yes	16.4 (318)	11.8 (30)	11.7 (18)	11.2 (10)	17.5 (25)	

<sup>a</sup> X<sup>2</sup> test of independence

\*Statistically significant p<0.05

**Table 4b: Adjusted Odds Ratios of Race & Ethnicity and Type of Medication Used\***

Variables	Race/Ethnicity compared to Non-Hispanic White				P value
	Hispanic	Black	Asian	Multiracial	
	Odd Ratio Estimates and 95% Confidence Limits				
Behavioral Challenges Medication	0.53 (0.39, 0.72)	0.72 (0.51, 1.03)	0.45 (0.26, 0.75)	0.90 (0.63, 1.29)	<.0001*
Total Problem Behaviors Medication	0.51 (0.38, 0.68)	0.62 (0.44, 0.87)	0.41 (0.25, 0.66)	0.85 (0.60, 1.21)	<.0001*
Hyperactivity Medication	0.56 (0.41, 0.77)	0.71 (0.49, 1.03)	0.32 (0.17, 0.61)	0.74 (0.50, 1.09)	<.0001*
Conduct Problems Medication	0.53 (0.36, 0.78)	1.05 (0.71, 1.57)	0.54 (0.28, 1.04)	1.09 (0.72, 1.66)	0.01*
Sleep Disturbances Medication	0.73 (0.48, 1.09)	0.68 (0.41, 1.14)	0.60 (0.31, 1.19)	1.13 (0.72, 1.77)	0.16

\* Results obtained from multivariable logistic regression models that included age (continuous), gender (male/female), primary caregiver education (High School or less, some college, bachelor degree, post-graduate degree), secondary caregiver education (High School or less, some college, college degree, post-graduate degree), and autism diagnosis (Autism, Asperger's, PDD/NOS) as covariates. <sup>b</sup> Results summarized from multiply imputing missing data 25 times.

\*Statistically significant p<0.05