

# A prospective Cross-sectional Cohort Assessment of Health, Physical, and Behavioral Problems in Autism Spectrum Disorders

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## ABSTRACT

**Objectives:** Autism spectrum disorder (ASD) is diagnostically defined by impaired socialization/communication and stereotypical behaviors. Health, physical, and behavioral problems have also been described in subjects diagnosed with an ASD, but have usually been examined in isolation. The purpose of the present study was to for the first time, systematically and quantitatively, examines health, physical and behavioral problems in a cohort of subjects diagnosed with an ASD.

**Materials and Methods:** A prospective cross-sectional ASD cohort (n=54) was evaluated for health, physical, and behavioral symptoms derived from parentally completed Autism Treatment Evaluation Checklist (ATEC) forms. The study protocol received Institutional Review Board (IRB) approval from Liberty IRB, Inc (Deland, FL).

**Outcomes:** The results showed the following occurrence of symptoms among study participants: gastrointestinal disturbances=48%, incontinence=57%, sleep problems=57%, eating disorders=94%, hyperactivity=67%, lethargy=26%, sensory processing problems=85%, anxiety/fear=74%, behavioral problems=89%, and obsessive-compulsive behaviors=92%. Of all of the areas examined, eating problems, behavioral problems, and obsessive-compulsive behaviors, were reported by the parents to be the most serious and problematic.

**Conclusions:** The present findings, taken together with previous research, suggest that subjects diagnosed with an ASD have significant health, physical, and behavioral problems beyond the symptoms evaluated in the diagnostic criteria used to diagnosis an ASD. The present findings also suggest the ATEC provides an economical means for healthcare providers to identify health, physical, and behavioral problems in subjects diagnosed with an ASD.

**Keywords:** ASDs, Asperger's, autistic, PDD-NOS, CARS, ATEC

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## INTRODUCTION

**A**utism spectrum disorder (ASD) is defined by qualitative impairment in social interaction, qualitative impairments in communication, and restricted repetitive and stereotyped patterns of behavior, interests, and activities in the Diagnostic and Statistical Manual of Mental Disorders, 4th Revision (DSM-IV) (1). Although an ASD diagnosis is defined by these three core features, other features, more physical or health related problems are reported in many of those diagnosed with an ASD. Issues often reported are: gastrointestinal (GI) disturbances (2,3); sleep problems (4); eating problems (5); hyperactivity or lethargy (6); self injury, aggressiveness, and destructive behavior (7); sensory processing abnormalities (8,9); anxiety or abnormal levels of fear (10,11); and obsessive-compulsive (OC) behavior (12).

Previous studies have been significantly limited in their examination of more physical or health related problems in subjects diagnosed with an ASD, because each have examined these problems in isolation from one another. The purpose of the present study was to systematically and quantitatively examine many of these other problems of a more physical or health related nature all at the same time in a prospective cohort of participants diagnosed with an ASD. □

## MATERIALS AND METHODS

### IRB and Consent

The study protocol received Institutional Review Board (IRB) approval from Liberty IRB, Inc (Deland, FL). The study complied with the American Psychological Association ethical standards in the treatment of participants and in obtaining informed consent. All parents signed a consent and Health Insurance Portability and Accountability Act (HIPAA) form and all received a copy.

### Overview

Participants with a DSM-IV diagnosis of autism, ASD, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger's Disorder were prospectively recruited from the community to participate in the study. After explaining the study and obtaining informed consent from the parent(s), each child

was evaluated by a trained professional using the CARS to confirm an ASD diagnosis and then the parents completed the ATEC.

### Participants

A total of 54 participants diagnosed with an ASD were prospectively recruited from the community by using flyers and word of mouth. Each child in the ASD group had been previously diagnosed by a professional. In the state of Texas, the only professionals that are allowed to diagnose ASD are either licensed clinical psychologists or medical doctors. To further evaluate each child's diagnostic accuracy, the CARS was completed on each child by one of the investigators (JKK) who has many years of experience in evaluating children with ASD. The study was designed to exclude children who had a history of Fragile X disorder, tuberous sclerosis, phenylketonuria (PKU), Lesch-Nyhan syndrome, seizure disorder, cerebral palsy, fetal alcohol syndrome, or any history of maternal illicit drug use. Detailed information was collected on each participant regarding age, race, gender, and year of birth. Table 1 summarizes the demographic information for the participants examined in the present study.

### Clinical Measures

Childhood Autism Rating Scale (CARS). The CARS is a 15-item behavioral rating scale developed to identify autism as well as to quantitatively describe the severity of the disorder. The items are: I. Relating to People; II. Imitation; III. Emotional Response; IV. Body Use; V. Object Use; VI. Adaptation to Change; VII. Visual Response; VIII. Listening Response; IX. Taste, Smell, and Touch Response and Use; X. Fear or Nervousness; XI. Verbal Communication; XII. Nonverbal Communication; XIII. Activity Level; XIV. Level and Consistency of Intellectual Response; and XV. General Impressions. Each item is scored from 1 (no pathology) to 4 (severe pathology) in 0.5 intervals. The CARS in previous research was shown to have a high concordance with an ASD clinical diagnosis using the DSM-IV criteria (13,14).

Autism Treatment Evaluation Checklist (ATEC). Among qualifying study participants, the study participant's parent completed an ATEC form developed by the Autism Research Institute (San Diego, CA) (15). The ATEC is a one-page form designed to be completed by

parents, teachers, or others who see the individual's behavior on a regular basis. The ATEC consists of four subtest scales: Scale I. Speech/Language/Communication (14 items – scores can range from 0-28), Scale II. Sociability (20 items – scores can range from 0-40), Scale III. Sensory/Cognitive Awareness (18 items – scores can range from 0-36), and Scale IV. Health/Physical/Behavior (25 items – scores can range from 0-75). The four subscale scores can be used to calculate a total score (total scores can range from 0-180). The scores are weighted according to the response and the corresponding subscale. The higher the subscale and total score, the more impaired the participant. The lower the subscale and total score, the less impaired the participant. The overall scores in each subscale and the total score can be extrapolated to determine the percentile of severity of the participant in comparison to score distributions provided by the Autism Research Institute. Pearson split-half (internal consistency) coefficients based upon evaluation of 1,358 participants revealed uncorrected *r* values as follows: Scale I. Speech/Language/Communication (0.920), Scale II. Sociability (0.836), Scale III. Sensory/Cognitive Awareness (0.875), Scale IV. Health/Physical/Behavior (0.815), and total score (0.942). The internal consistency reliability of the measure is high (0.94 for the total score). The ATEC has been successfully validated against other established autism testing metrics.

In the present study, Scale IV, Health/Physical/Behavior questions were examined to quantitatively measure health, physical, and behavioral problems among study participants. The following overall categories (with specific subcategory components) were examined: incontinence (bed wetting, wets pants/diapers, soils pants/diapers), GI disturbances (diarrhea, constipation), sleep problems, eating disorders (eats too much/too little, extremely limited diet), hyperactive, lethargic, behavior problems (hits or injures self, hits or injures others, destructive, shouts or screams, often agitated), sensory processing issues (sound sensitive, not sensitive to pain), anxiety/fear, and OC behaviors (obsessive speech, rigid routines, demands sameness, hooked or fixated). Each subcategory was scored using a 0-3 point scale derived from responses of severity answered on the ATEC form (not a problem = 0, minor problem = 1, moderate problem = 2, serious problem = 3),

and the frequency of the presence of symptoms (at least as a minor problem) was determined for each subcategory. This data derived from each subcategory was then examined to determine the frequency of the presence of symptoms (at least as a minor problem in one of the subcategories) in the overall categories.



### OUTCOMES

As summarized in Table 1, the study participants examined were between 2 to 16 years-old with a mean age of  $6.8 \pm 3.0$  years-old, and there were more male than female participants examined (male/female ratio = 6.7:1). Overall, the mean year of birth was  $2000 \pm 2.9$  (range = 1992 to 2005). Among study participants, Caucasians (74%) were more preponderant than minorities (26%). It was also observed that the overall mean CARS score was  $36.8 \pm 4.1$  (range = 24 to 50) for study participants, and more of the study participants experienced a regressive event in development at any time following birth (65%) than were non-regressive (35%). Overall, among study participants more were diagnosed with autism (59%) than those diagnosed with PDD-NOS or Asperger's disorder combined (41%).

As summarized in Table 2, the results showed that GI disturbances were reported in 48% of participants; incontinence was reported in 41% of participants; sleep problems in 57% of participants; eating problems in 94% of partici-

Descriptive	Information
<b>Sex / Age</b>	
Male / Female (ratio)	47 / 7 (6.7:1)
Mean Age in Years $\pm$ Std (range)	$6.8 \pm 3.0$ (2-16)
Mean Year of Birth $\pm$ Std (range)	$2000 \pm 2.9$ (1992-2005)
<b>Race (n)</b>	
Caucasian	74% (40)
Minorities <sup>1</sup>	26% (14)
<b>Autistic Disorder Characteristics</b>	
Mean CARS Score $\pm$ Std (range)	$36.8 \pm$ (24-50)
Regressive (n) <sup>2</sup>	65% (35)
Non-Regressive (n)	35% (19)
Autism (n)	59% (32)
Autism Spectrum Disorders (n) <sup>3</sup>	41% (22)

**TABLE 1.** A summary of the participants with an ASD diagnosis examined.

ATEC = Autism Treatment Evaluation Checklist; CARS = Childhood Autism Rating Scale

<sup>1</sup> Includes participants of Hispanic, Black, Asian, or Mixed Ancestry.

<sup>2</sup> Includes participants that had a regressive event in development at any time following birth.

<sup>3</sup> Autism spectrum disorders include participants diagnosed with pervasive developmental disorder – not otherwise specified (PDD-NOS) and Asperger's disorder.

Category	n (%)	*Mean Score (Std)
Subcategory		
<b>Incontinence</b>	31/54 (57%) <sup>1</sup>	
Bed wetting	22/54 (41%)	0.70 (0.98)
Wets pants/diapers	22/54 (41%)	0.63 (0.90)
Soils pants/diapers	17/54 (31%)	0.70 (1.11)
<b>GI Disturbances</b>	26/54 (48%) <sup>1</sup>	
Diarrhea	14/54 (26%)	0.35 (0.70)
Constipation	15/54 (28%)	0.43 (0.77)
<b>Sleep Problems</b>	31/54 (57%) <sup>1</sup>	0.89 (0.96)
Eating Disorder	51/54 (94%) <sup>1</sup>	
Eats too much/too little	39/54 (72%)	1.17 (0.93)
Extremely limited diet	45/54 (83%)	1.67 (1.05)
<b>Hyperactive</b>	36/54 (67%) <sup>1</sup>	1.17 (1.09)
<b>Lethargic</b>	14/54 (26%) <sup>1</sup>	0.35 (0.65)
<b>Behavioral Problems</b>	48/54 (89%) <sup>1</sup>	
Hits or injures self	15/54 (44%)	0.43 (0.81)
Hits or injures others	25/54 (46%)	0.67 (0.87)
Destructive	21/54 (39%)	0.48 (0.69)
Shouts or screams	36/54 (67%)	1.09 (0.94)
Often agitated	32/54 (59%)	0.91 (0.94)
<b>Sensory Processing Issues</b>	46/54 (85%) <sup>1</sup>	
Sound sensitive	40/54 (74%)	1.15 (0.92)
Not sensitive to pain	28/54 (52%)	0.74 (0.85)
<b>Anxiety/Fear</b>	40/54 (74%) <sup>1</sup>	1.07 (0.80)
<b>OC Behaviors</b>	50/54 (92%) <sup>1</sup>	
Obsessive speech	33/54 (61%)	1.07 (1.01)
Rigid routines	37/54 (68%)	1.04 (0.89)
Demands sameness	36/54 (67%)	0.93 (0.80)
Hooked or fixated	37/54 (69%)	1.69 (1.01)

**TABLE 2.** A summary of findings (n = 54).

Std = standard deviation

\*Scores from the ATEC Subcategories were from 0-3: 0 = Not a Problem, 1 = Minor Problem, 2 = Moderate problem, 3= Serious Problem.

<sup>1</sup> The overall number of subjects with a problem was derived by determining the number of unique subjects with at least a minor problem in any of the subcategories composing the overall category.

pants; hyperactivity in 67% of participants; lethargy in 26% of participants; sensory processing issues in 85% of participants; anxiety/fear issues in 74% of participants; behavioral problems in 89% of participants; and OC behaviors in 92% of participants. Of all of the areas examined, eating problems, behavioral problems, and OC behaviors, were reported by the parents to be the most serious and problematic. Among the subcategories examined, it was observed that extremely limited diet (83%), sound sensitive (74%), and anxiety/fear (74%), eats too much/little (72%), were among the most commonly reported among study participants, whereas soils pants/diapers (31%), constipation (28%), diarrhea (26%), and lethargy (26%) were among the least commonly reported among study participants. □

### DISCUSSION

The results of the present study suggest many subjects diagnosed with an ASD have sig-

nificant health, physical, and behavioral problems. The problems identified are not presently included in the ASD diagnostic criteria, but may be associated with significant morbidity. The results observed are consistent with previous observations of health, physical, and behavioral problems in subjects diagnosed with an ASD from many previous studies, and interventions designed to address these problems may significantly help to improve clinical outcomes in subjects diagnosed with an ASD.

For example, GI disturbances were reported in 48% of the children examined in the present study, with 26% reporting diarrhea, and 28% reporting constipation. This finding is consistent with observations made by Wang et al. (3). These investigators examined the GI health of 589 subjects diagnosed with an ASD and 163 of their unaffected sibling controls and found that parents reported significantly more GI problems in children with ASD (42%) compared with their unaffected siblings (12%). Wang et al. also stated that the two most common GI problems in children with ASD were constipation (20%) and chronic diarrhea (19%) (3).

It was observed among study participants that incontinence was reported in 41% of the subjects examined, with occurrences of bed wetting in 41%, wetting pants/diapers in 41%, and soils pants/diapers in 31% of the subjects examined. The parents of the study participants described that incontinence was one of the more challenging issues to deal with on a day-to-day basis. Although no studies could be found that specifically studied the overall occurrence of incontinence in subjects diagnosed with an ASD, Taira et al. examined 88 children diagnosed with autism using a questionnaire and found that bed-wetting was observed in 22 of the 88 children (28%) (16).

The current study found sleep problems were reported in 57% of the study participants examined. This finding is consistent with previous research by Miano and Ferri (17). These investigators found that children diagnosed with an ASD experience sleep problems similar to those of typically developing children, although the prevalence is markedly higher in children diagnosed with an ASD, occurring in 44-83% of school-aged children diagnosed with an ASD. They stated that caregivers usually report that insomnia is the most frequent sleep disorder; this included disorders of initi-

ating and maintaining sleep, restless sleep, bedtime resistance, co-sleeping, alterations of sleep hygiene, and early awakenings in the morning. Importantly, researchers have found relationships between sleep difficulties in subjects diagnosed with an ASD and challenging behaviors (18), and Johnson et al. stated that addressing sleep problems may improve daytime functioning and decrease family stress (19).

Eating problems were reported in 94% of the participants evaluated in the present study, with the occurrence of eating too much/too little in 72% and extremely limited diet in 83% of study subjects. This finding is consistent with previous research by Kodak and Piazza that estimated the prevalence of feeding problems in children diagnosed with autism to be as high as 90% (20). An extremely limited diet could conceivably result in nutritional deficiencies and research suggests that is the case. Zimmer et al. examined the frequency of selective eating and nutritional deficiency in 22 children diagnosed with autism and an age matched typically developing control group (21). They found that children with autism ate fewer foods on average than typically developing children and had a higher average intake of magnesium, and lower average intake of protein, calcium, vitamin B12, and vitamin D, and further, selective eaters were significantly more likely than typical controls to be at risk for at least one serious nutrient deficiency. Furthermore, interventional studies designed to help address potential nutritional deficiencies in subjects diagnosed with an ASD have revealed significant improvements in clinical symptoms. For example, Adams et al. in a randomized, double-blind, placebo-controlled treatment study of nutrient supplementation in 141 children and adults diagnosed with autism revealed the supplement group had significantly greater improvements than the placebo group on the Parental Global Impressions-Revised (PGI-R), and on its subscores for hyperactivity, tantrumming, overall, and receptive language (22). Similarly, Geier et al. conducted a placebo-controlled, double-blind study of 30 children diagnosed with an ASD who were randomized to receive the supplement L-carnitine or placebo for 3-months (23). Significant improvements were observed in CARS, and clinical global impression (CGI) scores. In addition, scores significantly improved in cognition, marginally in speech, and

non-significantly in total and sociability scores from ATEC testing.

The present study observed hyperactivity in 67% of the study participants examined. This finding is consistent with previous research by Charnsil and Sriapai who observed that hyperactivity in 60% of the children diagnosed with autism (24).

The current study found that sensory processing issues were reported in 85% of study participants, with occurrence of sound sensitivity in 74% and not sensitive to pain in 52% of the subjects examined. This finding is consistent with previous research by Geschwind that observed abnormal sensory processing in over 90% of children diagnosed with autism (25). In addition, Kern et al. observed that a combination of defensiveness and insensitivity that involves all of the sensory modalities (tactile, oral, auditory, vestibular, and visual systems) (8).

Anxiety and fear issues were observed in 74% of the participants evaluated in the present study. This finding is consistent with previous research by White et al. that observed clinically significant anxiety ranged between 11% and 84% in subjects diagnosed with an ASD (26). Evans et al. evaluated fears, phobias, anxieties, and behavior problems in subjects diagnosed with an ASD (27). They reported children diagnosed with an ASD had more situation phobias and medical fears, but fewer fears of harm/injury compared to controls. In addition, in the children diagnosed with an ASD, fears, phobias and anxieties were closely related to problem behaviors, whereas fears, phobias, and anxieties were less related to behavioral symptoms for the other groups of subjects.

It was observed that 89% of the study participants in the present had behavioral problems, with occurrences of aggressiveness in 89%, hits or injures self in 44%, hits or injures other in 46%, destructive behaviors in 54%, shouts or screams in 67%, and often agitated in 59% of the subjects examined. Many of the parents of the study participants examined reported that these behavioral problems were serious and problematic. These findings are in line with previous research. Kanne and Mazurek examined the prevalence of and risk factors for aggression were examined in 1,380 children and adolescents diagnosed with an ASD (28). They investigators described among the subjects examined 68% had demonstrated ag-

gression to a caregiver and 49% to non-caregivers. Robb found that 20% of children diagnosed with autism have symptoms of irritability and aggression that manifest as severe tantrums and deliberate self-injurious behavior, and that these symptoms can lead to impairment and distress in both home and school settings (29). Importantly, aggressive and disruptive behaviors are the highest predictors of stress in families (28,30) and are also predictive of a family seeking out-of-home placement (31). Moreover, studies suggest that these issues can be exacerbated with the onset of puberty (32).

OC behaviors were observed in 92% of study participants, with occurrences of obsessive speech in 61%, rigid routines in 68%, demands sameness in 67%, and hooked or fixated in 67% of the subjects examined. Jacob et al. described that OC behaviors in ASD can partially overlap with symptoms associated with obsessive-compulsive disorder (OCD) (33), and OCD was reported to be diagnosed in 17.4% of children diagnosed with an ASD (34).

### Strengths and Limitations

Among the strengths of the present study was the fact that data was collected prospectively on a cohort of participants diagnosed with an ASD, and so unknown potential biases/confounding regarding non-continuously collected cohorts of participants should have minimally impacted the present study. Another strength of the present study was the demographics of the cohort of participants diagnosed with an ASD examined in the present study appear to be similar to the recognized demographics of the general population diagnosed with an ASD, so that the results observed should be expected to be extendible beyond the cohort of participants diagnosed with an ASD examined in the present study. In addition, since the participants diagnosed with an ASD examined in the present study were wide-ranging with respect to age, gender, racial composition, and severity, potential outlier skewing of the data should not have significant impacted the results observed.

A further strength of the present study was collection of quantitative data on multiple different health, physical, and behavioral problems using the ATEC (a previously validated scoring instrument) in a cohort of participants

diagnosed with an ASD at a single time point. This argues that the observations made were not the result of mere chance observations, and supports the notion that subjects diagnosed with an ASD have significant, concurrent multiple health, physical, and behavioral problems. Further, the consistency of observations on multiple different health, physical, and behavioral problems made using the ATEC in comparison with previously studies by other investigators helps to support the validity of the ATEC as a testing metric in ASD populations.

Among the limitations of the present study is that participants examined were assumed to be on the autism spectrum based upon the fact that they were previously diagnosed with an ASD and a subsequent professional CARS evaluation. It is possible that other tests such as Autism Diagnostic Observation Schedule (ADOS) or Autism Diagnostic Interview, Revised (ADI-R) could have influenced whether the study participants were considered to be on the autism spectrum. Despite this potential limitation, CARS evaluations are well recognized metric of helping to establish an ASD diagnosis. Another limitation of the present study was that no control group was employed to evaluate the frequency and severity of the health, physical, and behavioral problems in comparison to control groups. As a result, it is not possible with certainty establish where the symptoms observed in study participants occurred at significantly higher rates in the ASD population in comparison to controls. Notwithstanding this limitation, the overall high prevalence and significant severity of the health, physical, and behavioral problems observed argue that the symptoms observed are of significant importance to the ASD population. Finally, another limitation of the present study was that it was not designed to evaluate the potential interrelationship between the various health, physical, and behavioral problems observed in the study participants. Future studies should further examine the potential interrelationship between the various health, physical, and behavioral problems observed in the present study in different ASD populations. □

### CONCLUSIONS

The present study is the first to systemically report on multiple health, physical, and behavioral problems commonly occurring in sub-

jects diagnosed with an ASD that traverse significantly beyond the three core features used to diagnose an ASD. The findings from this study, taken together with other research findings, suggest that there are significant health, physical, and behavioral problems in subjects diagnosed with an ASD beyond psychiatric disturbances. The economical identification of these problems by healthcare providers is possible using the ATEC form, and treatment of these problems may significantly help to reduce morbidity in subjects diagnosed with an

ASD. Future studies should further longitudinally evaluate health, physical, and behavior problems in other ASD populations using other metrics. □

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