## ORIGINAL PAPER

# **Autism Parenting Stress Index: Initial Psychometric Evidence**

Louisa M. T. Silva · Mark Schalock

© Springer Science+Business Media, LLC 2011

**Abstract** Data validating the Autism Parenting Stress Index (APSI) is presented for 274 children under age six. Cronbach's alpha was .827. As a measure of parenting stress specific to core and co-morbid symptoms of autism, the APSI is unique. It is intended for use by clinicians to identify areas where parents need support with parenting skills, and to assess the effect of intervention on parenting stress. Mean parenting stress in the autism group was four times that of the typical group and double that of the other developmental delay group [F(2,272) = 153; p < 001]. An exploratory factor analysis suggested three factors impacting parenting stress: one relating to core deficits, one to co-morbid behavioral symptoms, and one to co-morbid physical symptoms.

**Keywords** Autism · Parenting stress · Validation study · Assessment tool

# Introduction

Higher levels of parenting stress have been found in parents of young children with autism than in other disabilities (Estes et al. 2009). This is due to the challenges imposed by co-morbid behavioral and physical symptoms as well as core symptoms (Phetrasuwan and Miles 2009; Johnson

L. M. T. Silva (🖂) Teaching Research Institute, Western Oregon University, PO Box 688, Salem, OR 97308, USA e-mail: lmtsilvaqigong@comcast.net

M. Schalock

Teaching Research Institute, Western Oregon University, 345 Monmouth Avenue, Monmouth, OR 97361, USA e-mail: schalom@wou.edu

Published online: 10 May 2011

et al. 2009). The most common co-morbid symptoms in young children with autism are abnormal sensory responses (90%) (Leekam et al. 2007), sleep disruption (86%) (Liu et al. 2006), and gastrointestinal disorders (70%) (Ibrahim et al. 2009), followed by self-injurious behavior (34%) (Hartley et al. 2008), and aggression/irritability (22%) (Hartley et al. 2008). Between core and co-morbid symptoms almost every aspect of the child's functioning can be affected; this can challenge the coping skills and affect the mental health of parents (Montes and Halterman 2007). As such, it is of interest to clinicians and researchers to be aware of how parents are coping with the manifold demands of caring for a child with autism.

It is beneficial for parents to be involved in intervention strategies to help their children's disability, both for the benefit of increased coping skills, and for reduced stress (Diggle et al. 2003). There are several general measures of parenting stress available to evaluate the impact of intervention strategies on parenting stress (Abidin 1983; Berry 1995; Oster et al. 2002). But there is no measure of parenting stress that permits an analysis of the impact on the range of core and co-morbid symptoms seen in autism.

A 10-year research stream investigating the outcome of a 5-month, parent-delivered intervention for young children with autism demonstrated success in improving core and co-morbid symptoms, and reducing parenting stress in two randomized controlled trials (Silva et al. 2009; Silva et al., in press). The research is based on a model for autism that includes co-morbid as well as core symptoms with treatment directed at both. The model proposes that co-morbid sensory and self-regulatory symptoms are primary in autism, and core social/language delays and abnormal behaviors are secondary. Published outcomes data supports the model (Silva et al., in press). The research required the development and validation of two



instruments: (1) a caregiver report of core and co-morbid symptoms, the Sense and Self-Regulation Checklist (Silva and Schalock, in press); and (2) a parent/caregiver measure that could measure the outcome of intervention on the severity of parenting stress relative to these symptoms.

This article presents validation data and findings relative to the second measure—the Autism Parenting Stress Index (APSI)—in 274 children under six. Three research questions were explored:

Question 1 Do factor analyses support a core autism and co-morbid symptom structure for the sources of parenting stress in children with autism?

Question 2 Does the APSI produce reliable scores for parenting stress for children with autism?

Question 3 What is the prevalence and degree of parenting stress on each item of the APSI? Does the APSI discriminate between children with autism, children with other developmental disabilities and typically developing children on the basis of degree of parenting stress, as found in previously published research (Estes et al. 2009)?

#### Methods

## Instrument Development

The APSI was designed for clinical use to identify areas where parents need support with parenting skills, and to assess the effect of intervention on parenting stress. The items were developed and refined over a five-year period in conjunction with the development of a parent/caregiver measure assessing core and co-morbid symptoms in autism, the Sense and Self-Regulation Checklist (Silva and Schalock, in press). APSI items were informed by a knowledge of the normal developmental trajectory for selfregulatory milestones in the first three years of life, including self-regulation of sleep, digestion, self-soothing, orientation/attention, and the beginning of self-regulation of emotions and behavior in response to parental cues (Posner and Rothbart 2009). The areas in question were selected through an iterative process by conducting a review of over 100 interviews of parents with young autistic children, in which parents were asked to talk about areas of their children's functioning that were stressful to manage, and to name the three most stressful. Items fell into three categories: the core social disability, difficult-tomanage behavior, and physical issues. The formulation of the stress ratings was influenced by the excessively high rates of stress that were reported by parents in some areas, and were ranked from 'Not stressful', 'Sometimes creates stress', 'Often creates stress', 'Very stressful on a daily

basis', to 'So stressful that sometimes we feel we cannot cope.'

#### **Participants**

Data from 274 children ages 24 months to 72 months was collected for this study including: 107 children with Autism Spectrum Disorder (ASD), 28 children with other developmental delays (other DD), and 139 children who were developing typically. All projects took place with Institutional Review Board approval.

#### Data Collection

Autism Parenting Stress Index data on children with autism was collected from children receiving services for autism in state-sponsored, early intervention programs in multiple counties across Oregon over a period of 7 years. Data was collected as part of sequential research projects evaluating a parent-delivered intervention methodology. Inclusionary criteria for the autism group were: age under six, receiving state-sponsored early intervention services for autism, absence of other severe disability such as cerebral palsy, not planning on introducing new autism therapies for the duration of the study, and no psychotropic medication. Children were recruited from six regional early intervention programs in Oregon by invitation letter to all children in the program receiving services for autism and meeting age criteria. The primary researcher confirmed the diagnosis of autism received in previous diagnostic autism evaluations by DSM-IV criteria. A wide range of severity of ASD is represented in the sample. Because of the criteria excluding families who were planning on introducing new autism therapies during the duration of our studies, families entering our studies tended to not to be engaged in supplementary therapies outside of the early intervention program.

Data for the other DD group was obtained from a previous study investigating the effect of a parent-delivered intervention methodology in young children under six receiving early intervention services from state-sponsored programs for developmental delay and motor tone disorders. In that study, children meeting inclusion criteria were recommended to the study by the therapists serving children in the agencies where the study was carried out.

Parents of typically developing children were recruited to complete the surveys from one childcare center, three mother support groups, and one toddler drop-in play center in Oregon. Parents completed the surveys on a convenience basis. Inclusionary criteria for the children included: (1) between the age of three to six; (2) no educational or medical diagnosis of autism; (3) an absence of



Table 1 Demographic data

	, 1		
Demographic variable	Autism $n = 107$	Typical $n = 139$	Other developmental disabilities $n = 28$
Age			
Mean	3.85	3.98	2.64
Range	2–6	3–6	2–5
Gender			
Male	87	71	17
Female	20	68	11

developmental delay; and (4) an absence of chronic illnesses or medical conditions.

Table 1 provides demographic information on each group. The gender ratio for the autism group reflects the typical male-to-female gender ratio in ASD of 4:1. The gender ratio for the typical group is 1:1 as would be expected. And the male-to-female gender ratio for the other DD group is 1.5:1, which is consistent with that reported for children with developmental disabilities other than autism (Eme 1992).

#### Results

Question 1: Do factor analyses support a core autism and co-morbid symptom structure for the sources of parenting stress in children with autism?

Factor analysis was conducted in order to evaluate relationships between items and nature of stressors for parents of children with autism. Principal Axis extraction was utilized, iterating to communalities, and the extracted factors were subsequently obliquely rotated via Varimax rotation with Kaiser normalization. The four-factor solution derived for the sample of 107 parents of children with autism is presented in Table 5.

The first factor contained loadings for social development, communication, feeling close to child, acceptance by others, and future independence, and appeared to represent a broad dimension of core social and communication deficits in autism.

The second factor included loadings for tantrums/melt-downs, aggressive behaviors, self-injurious behaviors and difficulty making transitions. The second factor was consistent with typical co-morbid behaviors in autism.

Two additional factors emerged that were both related to co-morbid physical symptoms: bowel problems and toilet training delay, two areas of co-morbid physical symptoms; and sleep problems and diet/appetite problems, also common co-morbid physical symptoms in autism.

The results of the factor analysis were generally consistent with observations in the initial parent interviews

carried out during the instrument development phase of the study, when it was noticed that the three main areas of concern to parents were the core social problems, difficult-to-manage behaviors, and physical problems. The core autistic social and co-morbid behavior problems were well supported. Co-morbid physical problems as a factor was less cohesive as two separate factors emerged in these data. For analyses in Questions 2 and 3 we combine these two factors into one construct.

Question 2 Does the APSI produce reliable scores for parenting stress for children with autism?

Both internal consistency and test-retest stability were assessed for the APSI. Internal consistency estimates (Cronbach's Alpha) were calculated for the overall questionnaire for each population as well as for the three factors. These results are shown in Table 2. Overall scale alphas ranged from .732 for children with other developmental disabilities to .834 for typically developing children. Alpha was .827 for children with Autism Spectrum Disorder. At the construct level, alphas were generally lower. For parents of children with autism, the alphas were .792, .758 and .667 on the factors of core autism behaviors, co-morbid behaviors and co-morbid physical issues.

Test-retest stability estimates were calculated for the overall questionnaire with a sub-sample of parents of 18 children with autism at a 4-month interval. The test-retest coefficient was .882. Mean scores on the two administrations were stable across time at 22.22 and 22.28.

With this initial small sample, the overall APSI scale score demonstrates acceptable internal consistency and test–retest stability for parents of children with autism and other developmental disabilities. Internal consistency estimates at the factor level are approaching an acceptable level for core autism behaviors and co-morbid behaviors. Larger samples are needed to confirm these results and to determine whether the two physical factors should be combined or separated.

**Table 2** Internal consistencies of domains by autism spectrum disorder (ASD), typically developing, and other developmental disabilities (other DD)

Domain	Cronbach's	Number		
	Reliability ASD	Reliability typical	Reliability other DD	of items
Overall parental stress scale	.827	.834	.732	13
Core autism symptoms	.792	.703	.659	5
Co-morbid behaviors	.758	.710	.845	4
Co-morbid physical issues	.667	.650	.141	4



Question 3 What is the prevalence and degree of parenting stress on each item of the APSI? Does the APSI discriminate between children with autism, children with other developmental disabilities and typically developing children on the basis of degree of parenting stress, as found in previously published research (Estes et al. 2009)?

The distribution of responses on the APSI instrument for each group is shown in Table 3. Prevalence of stress was determined by the percentage of responses at "Often Creates Stress" or higher. Parents of children with autism have a higher prevalence of stress overall, on each factor, and on each item compared to the parents of other children. Overall, half (50.4%) of the parents of children with autism indicated that they were "stressed." This compares to 7.1% of parents of typically developing children and 23.6% of parents of children with other developmental disabilities.

At the factor level, nearly 60% of parents of children with autism indicated being stressed around the core autism behaviors. This is roughly twice as high an incidence as for parents of children with other developmental disabilities (32.9%) and nearly twenty times that for parents of typically developing children (3.5%). The prevalence of stress around co-morbid behaviors and physical problems in parents of children with autism was not quite so pronounced, but significant differences exist between the three groups on these factors as well.

Specific items about which the majority of parents expressed significant stress included: Social development, communication, tantrums/meltdowns, transitions, diet, acceptance and future independence. Stress for parents of children with autism was highest on items related to the ability of their child to communicate (77.6%) and acceptance of their child by others (72.2%). These parents were least stressed about feeling close to their child and their child's self-injurious behavior (19.6%), though still one in five parents felt stress about these issues.

A similar pattern was seen in parents of children with other developmental disabilities, though a smaller percentage of these parents expressed significant levels of stress. Parent of typically developing children were considerably less stressed on all items, though one in five (22.2%) did express significant stress about their child's tantrum or meltdowns. On average, parents of children with autism rated 1.34 items as a "5" (so stressful sometimes we feel we can't cope). This compares to an average of .08 items for parents of typically developing children and .21 items for children with other developmental delays. The top two items rated "5" for the autism group were tantrums/meltdowns, and concern for the future of your child living independently. These results are shown in Table 4.

To determine whether gender or age confounded these findings for each disability, group separate two-way ANOVAs were run. Neither gender nor age was found to be significantly related to parenting stress. For gender, neither gender [F(1,273) = 2.15, p = .144] nor the gender by disability interaction [F(2,272) = .247, p = .782] were significant. For age, neither age [F(4,270) = 2.34, p =.056] or the age by disability interaction [F(7,267) = 1.31,p = .247] were significant. Age is a stronger correlate with parental stress, as several of the items address issues that are developmental in nature. Within the group of children identified as having autism, a wide range of severity existed. To further investigate the relationship between parental stress and severity of autism, scores from the APSI were correlated with a well-established measure of autistic behaviors, the Pervasive Developmental Disorders Behavior Inventory (PDDBI). A positive and significant correlation between parental stress and the Autism Composite score from the PDDBI was found (r = .443, p < .001).

The discriminatory ability of the APSI was evaluated with ANOVAs, which showed significant group differences across total scale [F(2,272) = 153.0; p < .001].

To determine whether the APSI discriminated across groups at the factor level, a MANOVA was run on all factors. The MANOVA showed an overall significant group difference across factors using Pillai's Trace  $[F(6,540)=51.9;\ p<.001]$ . Post-hoc univariate ANOVAs indicated significant differences for each of the four factors, with F's ranging from 37.0 to 188.7.

An ANOVA was conducted at the item level. Each item also discriminated across groups, with Fs ranging from 12.9 (p < .001) on aggressive behaviors to 166 (p < .001) on ability to communicate. Post-hoc Scheffetest comparisons show that the APSI differentiates between parents of children with autism and typically developing children on every item with mean scores for the parents of children with autism being two to five times those of typically developing children. No significant differences were found between the parents of children with autism and children with other developmental disabilities for issues related to self-injurious behaviors, sleep problems, or bowel problems. Significant differences were found for the remaining eight items. These results are shown in Table 5.

# Discussion

In this paper, we demonstrate that the APSI is a reliable instrument for measuring parenting stress in young children with autism with alphas that compare favorably with three other instruments in common use (Abidin 1983; Berry 1995; Oster et al. 2002). The results reported here are consistent with reports that parenting stress is significantly



Table 3 Item description and prevalence in children with autism. (ASD Autism Spectrum Disorder)

Item	Stress ratings					Prevalence of stress	
	Not stressful (%)	Sometimes creates stress (%)	Often creates stress (%)	Very stressful on a daily basis (%)	So stressful sometimes we feel we can't cope (%)	for families of children with ASD (%)	
Overall scale							
Normally developing	68.7	24.2	5.1	1.4	.6	7.1	
Autism	24.4	25.2	20.7	19.3	10.4	50.4	
Other developmental disabilities	48.4	28.0	11.8	10.2	1.6	23.6	
Core autism behaviors							
Normally developing	78.3	18.3	2.6	.7	.1	3.5	
Autism	16.4	23.7	24.5	23.9	11.4	59.8	
Other developmental disabilities	35.0	32.1	19.3	12.1	1.4	32.9	
Co-Morbid behaviors							
Normally developing	44.3	27.1	6.2	1.6	.9	8.6	
Autism	20.2	23.7	15.1	13.3	7.7	36.1	
Other developmental disabilities	45.0	23.6	4.3	5.7	1.4	11.45	
Co-Morbid physical issues							
Normally developing	56.0	17.7	4.5	1.3	.6	6.3	
Autism	26.9	17.9	14.2	13.1	7.9	35.1	
Other developmental disabilities	45.7	17.1	7.1	8.6	1.4	17.1	
Your child's social development	13.7	17.1	7.1	0.0	1.1	17.1	
Normally developing	61.9	34.5	2.9	.7	.0	3.6	
Autism	5.6	29.9	37.4	19.6	7.5	64.5	
Other developmental disabilities		39.3	10.7	14.3	.0	25.0	
Your child's ability to communic		39.3	10.7	14.5	.0	23.0	
Normally developing	69.8	27.3	2.2	.7	.0	2.9	
Autism	3.7	18.7	24.3	38.3	15.0	77.6	
Other developmental disabilities	7.1	50.0	32.1	10.7	.0	42.9	
Tantrums/meltdowns	7.1	30.0	32.1	10.7	.0	42.9	
	20.1	57.6	16.5	3.6	2.2	22.3	
Normally developing Autism	7.5	25.2	24.3	20.6	22.4	67.3	
Other developmental disabilities	32.1	42.9	10.7	10.7	3.6	25.0	
Aggressive behavior	42.2	41.7	10.0	2.0	1 4	15.1	
Normally developing	43.2	41.7	10.8	2.9	1.4	15.1	
Autism	30.8	29.0	16.8	15.9	7.5	40.2	
Other developmental disabilities	71.4	14.3	.0	14.3	.0	14.3	
Self-injurious behavior	04.2	5.0	7	0	0	7	
Normally developing	94.2	5.0	.7	.0	.0	.7	
Autism	52.3	28.0	7.5	8.4	3.7	19.6	
Other developmental disabilities	75.0	14.3	7.1	.0	3.6	10.7	
Difficulty making transitions	64.0	20.0	2.0		-	5.0	
Normally developing	64.0	30.9	2.9	1.4	.7	5.0	
Autism	10.3	36.4	27.1	21.5	4.7	53.3	
Other developmental disabilities Sleep problems	46.4	46.4	3.6	3.6	.0	7.1	
Normally developing	64.0	27.3	7.9	.7	.0	8.6	
Autism	38.3	25.2	15.0	12.1	9.3	36.4	
Other developmental disabilities		14.3	10.7	10.7	3.6	25.0	



Table 3 continued

Item	Stress ratings					Prevalence of stress
	Not stressful (%)	Sometimes creates stress (%)	Often creates stress (%)	Very stressful on a daily basis (%)	So stressful sometimes we feel we can't cope (%)	for families of children with ASD (%)
Your child's diet						
Normally developing	61.2	29.5	6.5	2.2	.7	9.4
Autism	17.8	25.2	24.3	19.6	13.1	57.0
Other developmental disabilities	46.4	25.0	10.7	17.9	.0	28.6
Bowel problems (diarrhea, etc.)						
Normally developing	84.2	10.8	2.2	2.2	.7	5.0
Autism	19.5	18.7	16.8	9.3	5.6	31.8
Other developmental disabilities	53.6	28.6	7.1	10.7	.0	17.9
Potty training						
Normally developing	70.5	20.9	5.8	1.4	1.4	8.6
Autism	29.0	20.9	15.0	24.3	11.2	50.5
Other developmental disabilities	67.9	17.9	7.1	3.6	3.6	14.3
Not feeling close to your child						
Normally developing	86.5	10.1	2.9	1.4	.0	4.3
Autism	57.9	22.4	9.3	5.6	4.7	19.6
Other developmental disabilities	92.9	3.6	.0	3.6	.0	3.6
Concern for the future of your ch	aild being accepted	by others				
Normally developing	77.0	17.3	4.3	.7	.7	5.8
Autism	6.5	21.5	28.0	32.7	11.2	72.0
Other developmental disabilities	17.9	32.1	32.15	14.3	3.65	50.0
Concern for the future of your ch	iild living independ	ently				
Typically developing	97.1	2.2	.7	.0	.0	.7
ASD	8.4	26.2	23.45	23.45	18.7	65.4
Other developmental disabilities	21.4	35.7	21.4	17.9	3.6	42.9

Prevalence is defined as having a score higher than of the mean of the normally developing population plus 1 SD

higher for autism than other groups (Estes et al. 2009) and provide information about why that is so.

In particular, the APSI reported a mean parenting stress level in the autism group that was four times higher than the typical group, and twice as high as the other DD group. The factor analysis indicated three variables impacting parenting stress: one related to core symptoms, and two encompassing the full range of symptoms representing delays and difficulties in achieving self-regulatory milestones (tantrums, aggression, self-injurious behavior and difficulty making transitions; appetite/digestion, sleep and toilet training delays) (Posner and Rothbart 2009).

Our validation study for the Sense and Self-Regulation Checklist (SSC) was conducted with the same cohorts of children as this APSI validation study. In the SSC study, we found that the autism group was distinguished from the other groups by virtue of global self-regulatory delay (Silva et al., in press). In young children, unfolding self-regulatory abilities are supported by the parenting role, which is required to monitor and respond to the child's needs,

and stand in for the child's inability to regulate their environment and behavior. Consequently, it is not surprising to see that global self-regulatory delay on the SSC is associated with global parenting stress on the APSI. And while there is variability in parental interpretation of parenting stress, it is important to recognize that parenting stress is compounded when there are self-regulatory delays in multiple areas, and situations arise that are inherently stressful. For example, if a child has chronically disturbed sleep, then the parent is chronically sleep-deprived. If a child is sleep deprived, they are more prone to tantrums, which are harder to manage if the parent is sleep deprived, and the child has no language. When that child goes to preschool, difficulties in managing tantrums in a child without language can result in the child being sent home, which causes the parent to miss work, and results in increased parenting stress relative to sleep, tantrums, language, and concern for future independence.

The main difference between the APSI and general measures of parenting stress is that, recognizing the parenting skills required to manage the complex core and



**Table 4** Significant population comparisons: autism spectrum disorder (N = 107); other developmental disability (N = 28); typically developing (N = 139)

	Autism spectrum disorder	Other developmental disability	Normally developing	F
Stress	total			
M	22.93	11.75	5.41	153.0***
SD	10.43	6.73	5.18	
Core o	autism behavi	iors		
M	10.07	5.71	1.32	188.7***
SD	4.93	3.23	1.86	
Co-Mo	orbid behavio	ors		
M	6.61	2.82	2.42	52.5***
SD	4.19	3.42	2.22	
Co-Mo	orbid physica	l issues		
M	6.24	3.21	1.67	62.1***
SD	4.31	2.47	2.15	
Your c	child's ability	to communicate		
M	2.57	1.46	.34	166.0***
SD	1.33	.79	.56	
Tantru	ıms/meltdown	es.		
M	2.48	1.14 <sup>a</sup>	1.12 <sup>a</sup>	37.6***
SD	1.60	1.21	.92	
Aggre	ssive behavio	r (siblings, peers)		
M	1.48	$0.57^{a}$	$0.79^{a}$	12.85***
SD	1.45	1.07	.92	
Self-in	jurious behav			
M	$0.87^{a}$	$0.46^{ab}$	$0.06^{b}$	26.08***
SD	1.24	1.07	.28	
Difficu	ılty making tr	ansitions from on	e activity to anoth	
M	1.79	$0.64^{a}$	0.45 <sup>a</sup>	64.7***
SD	1.17	.73	.73	
Sleep	problems			
M	1.38 <sup>a</sup>	$0.86^{ab}$	0.45 <sup>b</sup>	19.5***
SD	1.55	1.33	.67	
Your o	child's diet			
M	1.98	$1.00^{a}$	.53ª	46.3***
SD	1.54	1.16	.81	
Bowel		iarrhea, constipati	ion)	
M	1.08 <sup>a</sup>	0.75 <sup>ab</sup>	0.25 <sup>b</sup>	18.9***
SD	1.40	1.01	.71	
Potty i	training			
M	1.79	0.61 <sup>a</sup>	$0.44^{a}$	37.8***
SD	1.61	1.17	.86	
Not fe	eling close to	-		
M	.81	0.14 <sup>a</sup>	$0.20^{a}$	15.3***
SD	1.28	.59	.55	
Conce	rn for the fut	ure of your child	being accepted by	
M	2.32	1.57	.32	115.6***
SD	1.32	1.69	.70	

Table 4 continued

	Autism spectrum disorder	Other developmental disability	Normally developing	F
Conce	ern for the fut	ure of your child liv	ving independen	ntly
M	2.36	1.50	.04	149.1***
SD	1.55	1.23	.22	

Degrees of freedom were (2, 272) for all comparisons; means sharing common superscripts letters a, b are not significantly different

\*\*\* p < .001, all two-tailed tests

co-morbid multiplicity of symptoms seen in young children with autism, it asks for parenting stress levels relative to specific symptom areas. Other measures of parenting stress focus on parent factors, such as loneliness and marital satisfaction (Berry 1995), or child factors, such as child distractibility or demandingness (Abidin 1983), but none focus on the particularities and complexities of caring for a child with autism. The APSI is not intended to diagnose dysfunction in the parent-child relationship, or to be a screening tool of parental mental health problems. Instead, it is designed to provide clinicians with an overview of how well parents are coping with the demands of autism care in its manifold aspects, in order to allow attention to be directed to areas where parents need additional support and skills. Within that overview, the category "so stressful that at times we cannot cope" can function as a red flag for clinicians.

Currently the clinical management of core and co-morbid symptoms in autism is parceled out to different specialties, and information pertaining to how the parent is coping with the different aspects of the child's function is not collected in one place. One advantage of the APSI is it assesses parenting stress related to multiple aspects of autism, opening up a view of parenting stress not possible in a world of assessment where these questions are typically asked in isolation. The APSI, if widely used, would bridge the worlds of professionals who tend to focus on sleep and digestive symptoms (e.g. pediatricians), with those focusing on problem behaviors (e.g. psychologists and psychiatrists), sensory problems (e.g. occupational therapists, early interventionists), and language/social skills (e.g. speech therapists, early interventionists). All members of the team could thus be in a position to benefit from an overview of the how the child's particular constellation of symptoms is impacting parenting stress.

Although there can be little doubt that co-morbid symptoms are an important part of autism, the understanding of co-morbid symptoms and their relationship to core features of autism is still evolving and there is no widely accepted theory of autism that includes co-morbid with core symptoms. The structure of the APSI permits an assessment of the large degree to which co-morbid



Table 5	Factor	analyses	for
A DCI			

<b>Table 5</b> Factor analyses for APSI		Component				
		1	2	3	4	
	Your child's social development	.623				
	Your child's ability to communicate	.571				
	Tantrums/meltdowns		.808			
Extraction method: principal component analysis	Aggressive behavior (siblings, peers)		.764			
	Self-injurious behavior		.597			
	Difficulty making transitions from one activity to another		.773			
	Sleep problems				.580	
	Your child's diet				.767	
	Bowel problems (diarrhea, constipation)			.840		
	Potty training			.827		
	Not feeling close to your child	.598				
Rotation method: varimax with	Concern for the future of your child being accepted by others	.828				
kaiser normalization. Rotation converged in six iterations	Concern for the future of your child living independently	.795				

symptoms impact parenting stress: two-thirds of the APSI items, and two out of three of the APSI factors refer to co-morbid rather than core features of ASD. Because the parent is the main resource for the child, and because of the chronic nature of the disability, it is important for clinicians to be aware of the contribution of co-morbid symptoms to parenting stress, and to provide prioritized support and intervention accordingly. Among other things, this offers the hope of providing intervention before parenting stress reaches crisis proportion.

One of the limitations of this study is that all data was collected in Oregon. Given that it was drawn from multiple counties across Oregon we are confident that it represents Oregon well but it may or may not be representative of the broader population. Further study of a wider geographic area with evaluation of the demographic characteristics of the respondents is planned. In addition, given the wide variety of severity and symptom presentation of children on the autism spectrum, more APSI data must be gathered on a larger number of families to more fully develop the factor analysis and understand the impact of core and co-morbid symptoms on parenting stress.

**Acknowledgments** The authors wish to gratefully acknowledge the families and early intervention programs that participated in our research. In addition, we wish to thank the Curry Stone Foundation and Northwest Health Foundation whose generous support made this research possible. Finally, we would like to thank Sharon Kadell, Nancy Ganson and Kristen Gabrielsen for their assistance with data collection and project management.

# References

Abidin, R. R. (1983). Parenting stress and the utilization of pediatric services. Children's Health Care, 11(2), 70-73.

- Berry, J. O. (1995). The parental stress scale: Initial psychometric evidence. Journal of Social and Personal Relationships, 12(3), 463\_472
- Diggle, T., McConachie, H. R., & Randle, V. R. (2003). Parentmediated early intervention for young children with autism spectrum disorder. Cochrane Reviews, (1):CD003496.
- Eme, R. F. (1992). Selected female affliction in the developmental disorders of childhood: a literature review. Journal of Clinical Child Psychology, 21, 354-374.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. Autism, 13(4), 375-387.
- Hartley, S. L., Sikora, D. M., & McCoy, R. (2008). Prevalence and risk factors of maladaptive behaviour in young children with autistic disorder. Journal of Intellectual Disability Research, 52(10), 819-829.
- Ibrahim, S. H., Voigt, R. G., Katusic, S. K., Weaver, A. L., & Barbaresi, W. J. (2009). Incidence of gastrointestinal symptoms in children with autism: A population-based study. Pediatrics, 124(2), 680-686.
- Johnson, K. P., Giannotti, F., & Cortesi, F. (2009). Sleep patterns in autism spectrum disorders. Child and Adolescent Psychiatric Clinics of North America, 18(4), 917-928.
- Leekam, S. R., Libby, S. J., Wing, L., & Gould, J. (2007). Describing the sensory abnormalities of children and adults with autism. Journal of Autism and Developmental Disorders, 37, 894–910.
- Liu, X., Hubbard, J. A., Fabes, R. A., & Adam, J. B. (2006). Sleep disturbances and correlates of children with autism spectrum disorders. Child Psychiatry and Human Development, 37(2), 179-191.
- Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A populationbased study. *Pediatrics*, 119(5), e1040–e1046.
- Oster, H., Morales, L., Andersen, R., Wold, C., Simon, P., & Gelberg, L. (2002). The Aggravation in Parenting Scale: Language application issues among Spanish speaking Latino families living in Los Angeles County. Academy for Health Services Research and Health Policy. Meeting. 19:17.

Phetrasuwan, S., & Miles, M. S. (2009). Parenting stress in mothers of children with autism spectrum disorders. Journal for Specialists in Pediatric Nursing, 14(3), 157-165.



- Posner, M. I., & Rothbart, M. K. (2009). Toward a physical basis of attention and self regulation. *Physics of Life Reviews*, 6(2), 103–120
- Silva, L. M. T., Schalock, M. & Gabrielsen (in press). The QST home program: RCT of a parent-delivered treatment for autism. *American Journal of Occupational Therapy*.
- Silva, L. M. T. & Schalock, M. (in press). Sensory and self-regulation checklist: Initial psychometric evidence and findings. *American Journal of Occupational Therapy*.
- Silva, L. M. T., Schalock, M., & Ayres, R. (in press). A model and treatment for autism at the convergence of Chinese medicine and Western science: First 130 cases. *Chinese Journal of Integrative Medicine*.
- Silva, L. M. T., Schalock, M., Ayres, R., Bunse, C., & Budden, S. (2009). Qigong massage treatment for sensory and self-regulation problems in young children with autism: A randomized controlled trial. *American Journal of Occupational Therapy*, 63, 423–432.

