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Abstract

Parents of children with an autism spectrum disorder (ASD) report higher stress levels than parents of typically developing children and parents of children with Down Syndrome. Research has shown that parents of children with ASD attribute the highest degree of parenting stress to their child's embarrassing disruptive behavior, lack of prosocial behavior, and inability to function independently. This study examined Parenting Stress Index (PSI) scores of six families with children with ASD participating in the Parent-Child Interaction Therapy (PCIT) Clinic at the University of Georgia. Participant PSI scores were compared to literature documenting specific stress profiles of parents of children with ASD. Based on the published literature, it was predicted that parents would score higher on certain subscales of the PSI. In the child domain, participants were expected to score highest on the Distractability/Hyperactivity, Reinforces Parent, and Acceptability subscales. In the parent domain, participants were predicted to score highest on Attachment, Role Restriction, and Depression. The results show that the hypothesis was rejected in all subscales except distractability/hyperactivity and acceptability. These results could be due to the small sample size or the use of all high-functioning participants.

Examining Parenting Stress for Parents of Young Children with Autism Spectrum Disorders

Parents of children with autism spectrum disorders (ASD) report significant levels of stress (Nachshen & Minnes, 2005; Roberts et al., 2003) and more stress than parents of typically developing children (Woolfson & Grant, 2006). Furthermore, parents of children with ASD report higher levels of stress than parents of children with Down's syndrome (Abbeduto et al., 2004). If it is known that parents are feeling significant levels of stress, it is important to attempt to reduce the stress. To do this, the origin of the stress must be identified. Research has shown that parents of children with ASD attribute the highest degree of parenting stress to their child's embarrassing disruptive behavior (Plant & Sanders, 2007), lack of prosocial behavior (Lecavalier, Leone, & Wiltz, 2006), and inability to function independently (Koegel et al., 1992).

Baker-Ericzen and colleagues (2005) used the Parenting Stress Index (PSI) and other assessments to measure the amount of stress in parents of children with and without ASD. The study included participants who had children enrolled in an inclusion pre-school classroom. The results showed that the parents of children with ASD exhibited significant levels of stress in their total stress scores and in areas influenced by the child, such as their personalities. Other potential stressors, such as the activities and characteristics of the parents, were not found to be significant sources of stress.

The current study seeks to identify the specific areas that cause stress for parents of children with ASD. Using the PSI and sampling parents of children with high-functioning ASD, it is predicted that the parents will score at significant levels of stress on the child domain in the Distractibility/Hyperactivity, Reinforces Parent, and Acceptability subscales. In the parent domain, parents are expected to score at a significant level in the Attachment, Role Restriction and Depression subscales.

Method

Participants

Participants were the parents of individuals, recruited from the community, who were already participating in a study at the University of Georgia. To participate in the original study, the child had to be between the ages of two and eight and be diagnosed with high-functioning ASD. Of the seven adult participants, six were females and one male. The ages ranged from 34 to 54 with a mean age of 41 years old. Of the six children, 50% were male and 50% female, with a mean age of four years and two months. All participants were Caucasian. Participants completed a variety of assessments before beginning the study, including the Parenting Stress Index. The study focused on an intervention program using Parent-Child Interaction Therapy (PCIT) to shape behavior and increase play between the parent and child.

Measure

The Parenting Stress Index (PSI; Abidin, 1995) is a self-reported 120 item instrument which uses a five point Likert scale ranging from strongly agree to strongly disagree. The PSI is designed to assess the levels of stress in a parent's life based on a variety of issues in both a child and a parent domain. The child domain focuses on specific behaviors or characteristics of the child that cause stress on the parent, including Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood and Acceptability. The parent domain focuses on the ways in which the parent's life causes stress for the parent, including Competence, Isolation, Attachment, Health, Role Restriction, Depression and Spouse. A total score combines the child domain and parent domain scores. A life stress score is also assessed but is not included in the total stress score. High scores in all subscales indicate higher levels of stress, and scores above

the 75th percentile are considered significantly elevated. The PSI has adequate reliability and validity data (Abidin, 1995).

Procedure

The participants completed the measures during their first visit to the PCIT clinic. The scores were converted to percentile ranks and compared against the normative data and to the 75th percentile cutoff. The measure took approximately 20 minutes to complete and was completed independent of the spouse or child.

Results

Parents reported significant levels of stress in the child domain at the 94th percentile and total stress score at the 82th percentile, but they did not show significant levels in the parent domain, in which they scored at the 65th percentile. Figure 1 shows the findings from current participants, normative data for typical children and normative data for children with developmental delays. Figure 2 displays the percentile ranks for the individual child domains on the PSI. Within the child domain, all subscale scores are significant except for Reinforces Parent. Figure 3 shows the subscale scores for the parent domain. The parent domain showed no significant elevation in individual subscales except for Isolation at the 75th percentile.

Discussion

These findings corroborate prior research, in that parents of children with ASD report high levels of stress, and more of that stress is due to child-related variables than parent-related variables. The child domain showed significantly elevated results, which indicates that children with ASD cause increased stress on parents. The subscales of Adaptability and Mood are the highest at the 95th percentile. When Adaptability is elevated, it indicates that tasks are made more difficult by the child because they are unable to adapt to changes. Frequently, children with ASD

need to follow schedules, and anything that disrupts the schedule can cause extra stress to the child and parent. The Mood subscale is high when children are unhappy, depressed, frequently cry and do not show signs of happiness. The hypothesis was supported in the Demandingness scales, which scored at the 90th percentile, and the Distractibility/Hyperactivity and Acceptability subscales, which both had scores at the 85th percentile. Demandingness is elevated when the child places demands upon the parent; the parent feels as if he or she is always being pulled by the child, sometimes even physically. Distractibility/Hyperactivity refers to when the parent feels stress because the child is overactive, has a short attention span, does not listen to directions, and engages in a variety of other activities frequently observed in Attention Deficit and Hyperactivity Disorder. High scores in Acceptability occur when the child does not meet the expectations the parent had.

Contrary to the hypothesis, Reinforces Parent was the lowest subscale at the 55th percentile. It was predicted to be high because of the frequent language barrier and the likelihood for children with ASD to not make eye contact. These behaviors may have been less problematic for the parents in this study because all the children were high-functioning.

The hypothesis was rejected in the parent domain because Attachment, Role Restriction and Depression were all below the 75th percentile. High Attachment scores result when parents have a cold pattern of parenting because they do not feel an emotional closeness or when the parent is unable to perceive the child's needs and feelings accurately. Role Restriction is a surprising subscale in this domain because it was thought that parents would feel very stuck in their role as a parent of a child with ASD and unable to fulfill their other roles, such as spouse and employee. Depression was equal to normative data at the 50th percentile. Isolation was the single significant subscale within the parent domain. Considerable stress is placed on the parents

because they receive little support from others and feel as if no one understands all they have to endure. Competence was the lowest at the 40th percentile, indicating that parents are assured in their parental abilities.

Limitations in this study include the high level of functioning of the children and small sample size. The high-functioning level of the children implies that the behavior exhibited would be less problematic than those with more severe forms of the disorder. The small sample size allowed slight variations in each participant to greatly influence the overall mean in each category. Additionally, the PSI norms were established in 1995. Updated normative data could influence the comparison of parents of children with ASD to parents of typically developing children.

Future research may utilize a larger sample size to be able to generalize data across a larger population. These studies may compare children with ASD to a control group without ASD or compare children with ASD to children with other special needs such as Down's syndrome. Future research may also compare results of assessments before and after Parent-Child Interaction Therapy, which teaches parents to play with their child and to control behavior in positive ways.

Figure 1. Comparison of PCIT and normative scores on the PSI.

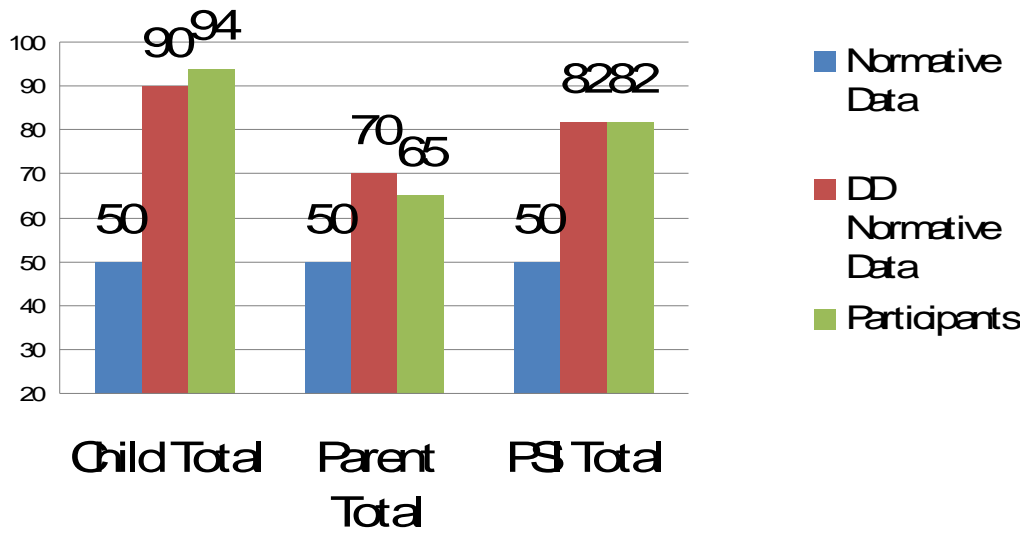


Figure 2. Child domain scores on the PSI. DI- Distractibility/Hyperactivity, AD- Adaptability, RE- Reinforces Parent, DE- Demandingness, MO- Mood, AC- Acceptability

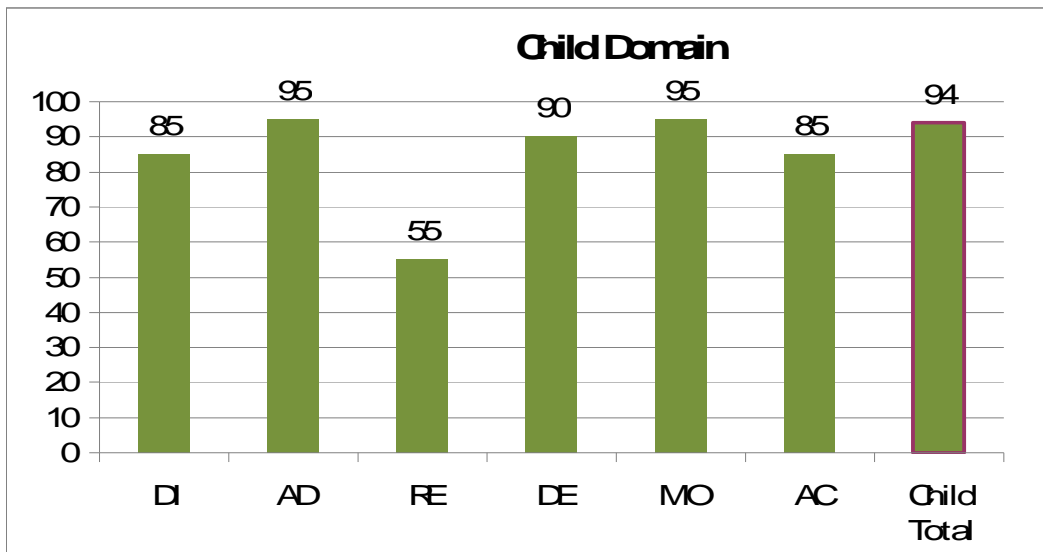
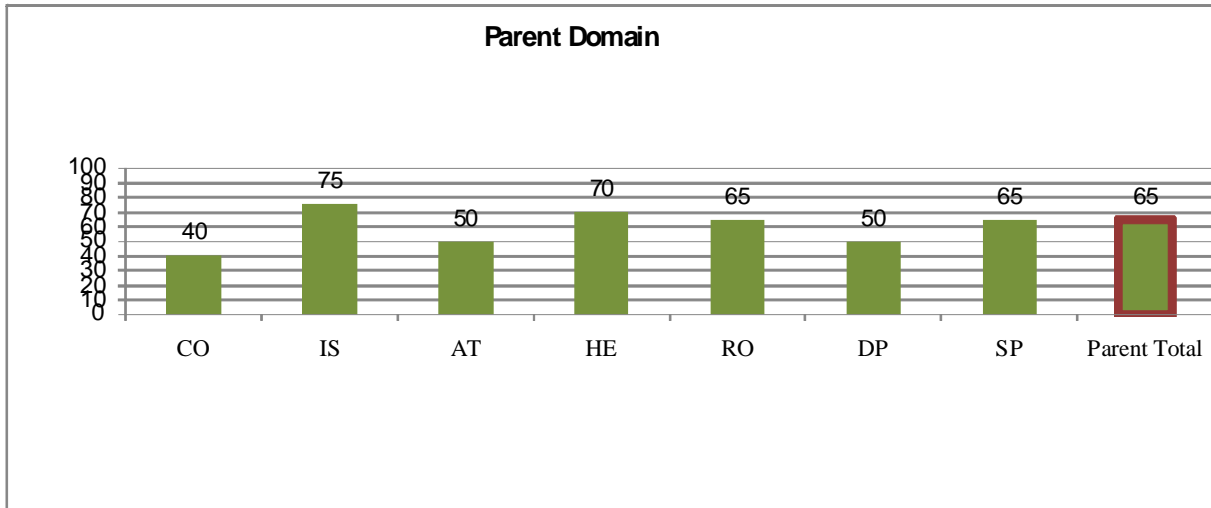


Figure 3. Parent domain scores on the PSI. CO- Competence, IS- Isolation, AT- Attachment, HE- Health, RO-Role Restriction, DP- Depression, SP- Spouse



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