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Parenting Stress on Mothers of Children with Autism

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PARENTING STRESS ON MOTHERS OF CHILDREN WITH AUTISM

A Thesis

by

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ABSTRACT

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Recent research has underscored that having a child with autism can be particularly stressful for parents. The purpose of the current study was to identify sources stress in mothers of children with an autism spectrum disorder (ASD) compared with mothers of typically developing children (TDC). A total of 33 mothers were recruited in this study; 18 mothers had at least one child with ASD and 15 mothers had at least one typically developing child. The results showed higher levels of stress in the ASD group compared to the TDC group. The main source of stress for the mothers in both groups was their child's maladaptive behaviors.

DEDICATION

The completion of my thesis studies would not have been possible without the love and support of my family. My husband, Albert Sanchez, who has been very supportive and understanding of this experience, my son Alan A. Sanchez, who throughout this process has been an outstanding patient child. My parents Jose and Juanita Cantu, my sister, Selene Cantu, my brothers Addiel and Edgar Cantu who have believed in me all this time and have helped me take care of Alan whenever possible, especially my mom, thanks Mom. Thank you for your love, support and overall patience.

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CHAPTER I

REVIEW OF LITERATURE

Autism was first identified as a syndrome by Kanner in 1943 when he noted an unusual condition hallmarked by social aloofness, impaired social interactions, and disturbance in language development (Phetrasuwan & Miles, 2009). Autism Spectrum Disorders (ASD) is a complex neurodevelopmental disorder that is usually diagnosed in children before age 3 (Altevogt, Hanson, & Leshner, 2008). Social interaction in children with autism is a major characteristic; compared to typically developing children, children with autism exhibit severe and persistent deficits in social behavior (Ingersoll, Schreibman, & Stahmer, 2001).

ASD is a cluster of disorders that affects each individual differently with varying degrees of severity (Twoy, Connolly, & Novak, 2007). ASD is equally likely to occur across all ethnic and socioeconomic backgrounds (Bertrand, et al. 2001). The number of children diagnosed with ASD has been rising, perhaps due to better assessment and diagnosis in recent years (Phetrasuwan & Miles, 2009). The Center for Disease and Control and Prevention (CDC) estimates that an average of 1 in 110 children in the United States has an ASD, and ASD occurs 4 to 5 times more often in boys than in girls. The causes of ASD are unknown. Evidence now suggests that the environment may play a significant role in triggering ASD, probably through a complex interaction with genetic

susceptibilities (Altevogt, Hanson, & Leshner, 2008). ASD, similar to other neurodevelopmental disabilities, is generally not "curable," and chronic management is required (Myers & Johnson, 2007). Parents may suspect ASD in a child as young as 12 to 15 months but formal diagnosis is made most reliably in the preschool period or upon starting school (Bertrand, et al. 2001). In the pediatric population, ASD is more common than some of the better known disorders such as diabetes, Down's syndrome, or spinal bifida (Twoy, Connolly, & Novak, 2007). Most children with ASD remain within the spectrum as adults and, regardless of their intellectual functioning, continue to experience problems with independent living, employment, social relationships, and mental health (Myers & Johnson, 2007). Most children with ASD will remain dependent all their lives; only a small percentage ever achieve regular paid employment (Bouma & Schweitzer, 1990). Children are likely to be dependent for longer, placing demands on their parents across the lifespan requiring quantitatively different support from typically developing children (Woolfson, & Grant, 2006).

The National Institute of Neurological Disorders and Stroke (NINDS) reports that social interaction in a child with ASD may appear to develop normally, but then at a young age, perhaps regress and then begin to withdraw and become indifferent to social engagement and fail to respond to their names and often avoid eye contact with other people. Children with ASD also lack empathy and don't know how to play interactively with other children. Those with the full-blown syndrome engage in repetitive behaviors such as rocking and twirling or in self-abusive behavior such as biting, head-banging and also have sleep problems, mostly insomnia (Ghanizadeh, Alishahi, & Ashkani, 2009). Several studies have found that certain restricted and repetitive behaviors are less

apparent in very young children and that some may not emerge until later in development (Bishop, Richler, & Lord, 2006). Hughes (2009) reported that repetitive behavior was related to social incompetence and could predict the severity of autism symptoms at three years.

Children with ASD experience language impairment, sensory problems,(including taste, smell), as well as visual and auditory processing problems (Ghanizadeh, Alishahi, & Ashkani, 2009). As mentioned, there is no cure for autism, however, therapies and behavior interventions are designed to remedy specific symptoms and can bring about substantial improvement (NINDS, 2009). Medications have not been proven to correct the core deficits of ASDs and are not the primary treatment (Myers & Johnson, 2007). Therapists use highly structured and intensive skill-oriented training sessions to help children develop social and language skills, such as Applied Behavioral Analysis (NINDS, 2009). For example, parent education programs that teach parents naturalistic strategies to increase their child's communication have been shown to result in increased skills among children and concomitant decreased levels of parent stress and depression (Baker-Ericzen, Brookman, & Stahmer, 2005).

Caring for a child with ASD can be challenging and extremely demanding (Twoy, Connolly, & Novak, 2007). It places high emotional demands on parents, which could affect their well-being as well as that of families. A study by Konstantareas & Homatidis (1989) found that self-abusive behavior was the best predictor of stress for both parents. Twoy *et al.* (2007) also cited stressors which included the day-to-day levels of stress arising from parenting, the parent's lack of confidence in handling the child's behavior and the lack of supportive services to meet the needs of the affected child. A

problem with communication and the realization that there is no cure for ASD are additional stressors experienced by parents. Social support has been shown to reduce the negative impact of different kinds of stressors (Sepa, Frodi, & Ludvigsson, 2004).

Parenting stress has been conceptualized as a condition where the different aspects of parenthood result in a perceived discrepancy between situational demands and personal resources (Sepa, Frodi, & Ludvigsson, 2004). Parenting a child with a developmental disability has been shown to be particularly stressful for parents as they respond to the unique challenges presented by their child's disability (Hoffman, Sweeney, Lopez-Wagner, Hodge, Nam, & Botts, 2008). The demands of raising a child with autism create family stresses that include communication problems (language delay, nonverbal), poor quality of life (no social life) and concerns about whether the child an ASD will be accepted by society (Lin, Tsai, & Chang, 2008). Mothers, being the primary caregivers, can experience more stress raising a child with autism (Montes & Halterman, 2008) than a typically developing child and also have poorer mental health than the general population (Ghanizadeh, Alishahi, & Ashkani, 2009). Bacon and Schweitzer (1990) found that the sources of stress for the family, who has a child with autism, may result from the extreme disruptions to daily family life produced by the behavioral problems of the child.

In addition to the stress of the child, parents often experience stigma from society and have ongoing concerns about their children's uneven developmental progress (Phetrasuwan & Miles, 2009). However, Montes & Halterman (2008) found that mothers of a child with autism were indistinguishable from mothers in the general population with respect to having a close relationship with their child, being angry with their child, or

coping with parenting tasks. The psychological legacy in which mothers were blamed for their children's autism disorder lingers and may contribute to the social stigma some mothers feels (Kuhn & Carter, 2006).

Research has shown that parents of children with ASD have sources of stress which include stress related to the child's uneven intellectual profiles, pervasive disruptive behaviors and the requirement of long-term care (Baker-Ericzen, Brookman, & Stahmer, 2005). Mothers of a child with an ASD also have reported poorer sleep quality (Hughes, 2009) and lower levels of emotional well being (Phetrasuwan & Miles, 2009).

These stresses on mothers can also have an effect on marriage itself, which consists of poor marital relationships (Tunali & Power, 2002). Although the data are not consistent, there is evidence that a child with autism in the family can stress the marital relationship and decrease marital satisfaction (Rivers & Stoneman, 2003). Parents, especially mothers, have to spend a lot of time with the child; so, they have less social contacts with family members, relatives, and the community (Ghanizadeh, Alishahi, & Ashkani, 2009). In some cases communities lack of understanding the behavior that children with ASD exhibit can have a huge impact on mothers, which could cause a high level of stress. Tunali and Power (2002) reported that mothers of an ASD child engaged in more leisure activities with extended family members because the extended family tends to accept the child. Between the amplified stress in their lives and feelings of estrangement from a world of "typical children," parents of children with special needs frequently report feelings of anxiety, depression, loss, loneliness, and hopelessness (Ainbinder et al, 1998).

Lin, Tsai, & Chang (2008) reported that raising a child with autism created the dilemma of choosing between jobs, life planning and caring for their children. Some mothers have lost their job due to the demands of raising a child with ASD. The families of children with ASD usually have lower levels of income. The cost for caring for children with ASD is twice as much as children without ASD (Ghanizadeh, Alishahi, & Ashkani, 2009) which causes a burden on both of the parents. Children with ASD need special attention, treatments, medications, and therapy, where a typically developing child might not. Also it should be noted that some of the support might not be available in some cities, so some mothers feel the need to travel to where there is the help they need and this could affect the families' income.

The family size could also be associated with the greater levels of family stress (Bacon & Schweitzer, 1990). Mothers may feel that they are not complying in the role of being a mother with other children in the household when they have to pay special attention to the child with ASD, which could have an effect with siblings. Gutpa (2007) reported that parents of children with developmental disabilities reported higher levels of role restriction and depression compared to other groups. This can cause a problem with siblings in the family. For example, approximately one-third of mothers spend more time taking care of their ASD child than his/her siblings, leading the latter to feel neglected (Lin, Tsai, & Chang, 2008). Ghanizadeh, Alishahi, and Ashknai (2009) report that since siblings may provide opportunities for social interactions, the siblings of children with ASD may also have an important role in this regards and that sometimes, the families have to clarify the reason or justify the behaviors of the children to others; this is not easy

at all, especially when the others may not have knowledge of what the symptoms and characteristics of ASD are.

More parents are raising children with a diagnosis of autism than ever before (Kuhn & Carter, 2006). Kuhn and Carter (2006) also mention that there are increasing efforts to involve parents of children with an ASD in interventions. One of life's biggest challenges is coping with stressful situations beyond one's control (Tunali & Power, 2002). However, the coping strategies of the parents change over time (Ghanizadeh, Alishahi, & Ashkani, 2009). Some of those changes in coping strategies as reported parents were the use of treatment services and support from members of their family (Gray, 2006). Increased parenting stress has been repeatedly identified as a risk factor for higher levels of child disruptive behavior problems as well as maladaptive parenting practices (Williford, Calkins, & Keane, 2007).

Proposed Study

The findings reviewed above suggest that parenting a child with autism can be very stressful, especially for mothers. Accordingly it is reasonable to hypothesize that mothers of children with autism will develop more stress than those mothers of typically developing children. The hypotheses of the study are:

1) Compare the stress level of mothers who have a child with ASD and mothers who have typically developing children. My hypothesis is that parents with ASD children experience more stress.

2) Examine sources of stress for mothers with a child with ASD. Hypothesized sources of stress include the high levels of the ASD child's maladaptive behaviors and low levels of the ASD child's adaptive behavior skills.

CHAPTER II

METHODOLOGY AND FINDINGS

Participants

A total of thirty-three mothers were recruited to participate in this study. Eighteen mothers were in the autism spectrum disorder group (ASD) and fifteen mothers were a part of the typically developing children group (TDC). This study included one African American, two White, and the remaining participants were Hispanic. Other demographic variables of participants are summarized on Table 1. The participants were recruited within a radius of about 20 miles from a large metropolitan statistical area near the Mexican border in south Texas.

ASD Group

Eighteen mothers were recruited who had a child with autism spectrum disorder. Out of the eighteen families who disclosed age of diagnosis, the range of age was 2-6 years and the median age was 4 years. Four mothers in the ASD group reported a diagnosis of Autistic disorder, four reported to have Asperger's Disorder, and the majority (7) reported that their child was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified.

TDC Group

Fifteen of the thirty-three mothers were a part of the comparison group that had at least two typically developing children who had not received a diagnosis of autism spectrum disorder and were closely matched in age with children in the ASD group.

Table 1. Other Demographic Variables

	ASD	TDC		ASD	TDC
Mother's Age	24-45	23-45	Own or Rent Home		
Median Age of Mothers	35	34.5	Own	15	11
Marital Status			Rent	3	4
Single	1	2	Employment		
Married	14	10	Yes	7	4
Living with partner	1	2	No	11	11
Divorced	2	1	Number of Medications		
Mother's Education			0	9	0
Some High School	2	0	1	4	0
High School Diploma	3	2	2	4	0
Some College	10	10	3	1	0
Bachelor's Degree	2	1	Family Support		
Master's Degree or higher	1	2	0	1	2
Father's Education			1-2	7	3
Some High School	1	4	3-4	8	7
High School Diploma	3	4	5-6	1	1
Some College	8	3	7-8	1	2
Bachelor's Degree	7	3	Social Support		
Master's Degree or higher	2	1	0	0	2
Annual Income			1-2	9	13
10,000-20,000	2	2	3-4	8	0
20,000-40,000	8	3	5-6	1	0
40,000-60,000	4	5			
60,000-higher	4	5			

Measures

A demographic questionnaire (see Appendix A) was used to collect the basic background information about the participants in the ASD group and the TDC group which can be referred to in the "Participants" section. Mothers in the ASD group

completed the Parenting Stress Index-Short Form (PSI-SF, Abidin, 1995), which was used to assess the stress level in mothers. The PSI-SF is composed of 36-items that measure stress in the parenting role. This measure is composed of 3 domains: Difficult Child (DC), Parent-Child Dysfunctional interaction (P-CDI), and Parent Distress (PD). The DC subscale focuses on some of the basic behavioral characteristics of children that make them either easy or difficult to manage. The P-CDI subscale focuses on the parent's perception that his or her child does not meet the parent's expectation, and the interactions with his or her children are not reinforcing to him or her as a parent. The PD subscale determines the distress a parent is experiencing in his or her role as a parent as a function of personal factors that are directly related to parenting. There are five responses that mothers answer on a Likert-type scales ranging from *strongly agree* to *strongly disagree.* This measure takes about 10-15 minutes to complete according to Abidin (1995).

To identify potential sources of stress stemming from the ASD child's adaptive behavior skills and incidence of maladaptive behaviors, mothers also completed the Vineland Adaptive Behavior Scale-II (VABS-II) Parent/Caregiver Rating Form, (Sparrow, Cicchetti, & Balla, 2009). The VABS-II is used to assess four main domains which include: Communication, Daily Living Skills, Socialization, and Motor Skills. Each item within the set is scored as a 0 (never), 1 (sometimes; partially), or 2 (usually). The VABS-II also includes an index that measures maladaptive behavior of the child with autism. This measure takes about 20-60 minutes to complete according to Sparrow, Cicchetti, & Balla (2009).

Procedure

Verbal and email recruitments were made for the ASD group through a local autism support group (see Appendix C). The TDC group was recruited verbally and email at a local university and through the autism support group (see Appendix D). Once appointments were scheduled with participant, convenient meeting locations (local church and coffee shop) were used for participants to conduct the questionnaire sessions. Each participant was given a packet that included an informed consent (see Appendix E), the demographics questionnaire, the VABS-II, and the PSI-SF. Each questionnaire packet was assigned a unique number for data analysis purpose. None of the participants used personal information such as names or addresses. Once the informed consent was read by the participants, the demographics questionnaire was completed. Then the mothers were asked to complete the PSI-SF regarding the child with autism. The VABS-II questionnaire was then completed by the mother about the child with autism. The TDC group followed same instruction to complete the demographic questionnaire, PSI-SF and VABS-II questionnaire regarding their typically developing children that was closest to age with the ASD group.

Before the participants tuned in their packet of questionnaires, questionnaires were checked to avoid any missing data. Once the questionnaires were reviewed, they were sealed in an envelope. The total session time ranged between 45-90 minutes for each group.

Results

Properties of Measures Planned for Analysis

The mean and standard deviation of the PSI-SF total percentile score was 86.70 (31.46). According Abidin (1995) mothers who obtain a total score at the 90th percentile are experiencing clinically significant levels of stress. The skewness value of .51 and kurtosis value of -.536 indicated that the scores were positively skewed and platykurtic in shape. Platykurtic distributions have relatively the same number of scores in the extremes versus near the mean so that they are less peaked compared to a normal distribution, respectively. A one-sample Kolmogorov-Smirnov (KS) test was conducted to evaluate the assumption of normality. The results indicated KS .59, (p> .05) that the data were indeed normal. Cronbach's alpha coefficients for the current sample of mothers in the ASD and TDC groups had an overall total PSI-SF score of .965. The Cronbach's alpha for the three subscales were as follows: Parental Distress .832, Parent-Child Dysfunctional Interaction .786, and Difficult Child .856. The Defensive Responding subscale of the PSI-SF is a type of validity subscale which measures the extent to which a parent tends to minimize their child's problems. Scores less than 10 on the Defensive Responding subscale suggest significant defensiveness in completing the entire scale. The mean and standard deviation of the Defensive Responding scale for the ASD and TDC groups were, respectively, 21.78 (5.58) and 14.9 (5.95). These means were significantly different, $\underline{F}$ (1,31)= 8.46, p<.007. While both groups, then, were open about admitting child problems, the ASD group was more amenable to disclosing problems than the TDC group.

The mean and standard deviation of the Adaptive Behavior Composite score from the VABS-II was 83.88 (21.88). According to Sparrow et al.(2009) this sample was performed at an average when compared to a normative sample. The VABS-II adaptive behavior composite score distribution had a skewness value of .87 and the kurtosis value of 1.53 indicated that the scores were positively skewed and leptokurtic in shape. Leptokurtic have relatively few scores in the extremes but have many scores near the mean which are more peaked compared to a normal distribution, respectively. Cronbach's alpha coefficients for the total sample of children with ASD and TDC groups was .99 for total adaptive behavior composite score. A one-sample Kolmogorov-Smirnov (KS) test was conducted to evaluate the assumption of normality. The results indicated KS .55, (p> .05) that the data were indeed normal.

The mean and standard deviation of the Maladaptive Behavior Index score from the VABS-II was 17.97 (4.17). A score between 1 and 17 means that the child in an average level in behavior problems. The higher the score means more behavior problems. The skewness value of -1.54 and the kurtosis value of 3.19 showed that the scores were negatively skewed and leptokurtic in shape from a normal distribution. The Cronbach's alpha coefficients for the total sample of children with ASD and TDC group as .91 for total maladaptive behavior index score. The Cronbach's alpha for the three subscales of the VABS-II were as follows: Communication .945, Daily Living Skills .945 and Socialization .895. The KS test was also conducted to evaluate the assumption of normality and the results indicated (KS) .82, (p>.05) that the data were indeed normal.

Statistical Comparison

The PSI-SF scores were entered as the dependent variable into an analysis of variance (ANOVA) with the ASD group versus the TDC group as the between-subjects factor and the three PSI-SF subscales as the within-subjects factor. The main effect of groups was significant, $F(1,31) = 22.40$, $p < .00005$, as was the main effect of subscales, $F(2,62) = 12.56$, $p < .00003$; the groups by subscales interaction was not statistically significant, $F(2,62) = 2.13$, $p < .13$. For the group main effect, the effect size (partial eta squared) was .419, and observed power was .996. For the subscale main effect, the effect size (partial eta squared) was .288 and observed power was .995.

The overall PSI-SF mean and standard deviation for the ASD group was 35.35 (1.90) and for the TDC group was 22.04 (2.08). The overall mean and standard deviation for Parental Distress subscale was 29.75 (1.82), for the Parent-Child Dysfunctional Interactions subscale was 24.40 (1.43), and for the Difficult Child was 31.94 (1.72). Pair-wise comparisons to examine differences among subscale scores were performed using Tukey's least significant difference at the .05 level of confidence. The only pair-wise comparison to reach statistical significance was that the mean of the Difficult Child subscale was greater than Parent-Child Dysfunctional Interaction.

Means and standard deviations for the three subscales for the ASD and TDC groups are broken down by each of the three PSI-SF subscales are shown in Table 2.

Table 2. Means and Standard Deviations for ASD and TDC groups

PSI-SF Subscales	ASD Groups (*n=18)*	TDC Groups *(n=15)*
Parental Distress	34.83(2.46)	24.67(2.70)
Parent-Child Dysfunctional Interactions	31.00(1.936)	17.80(2.12)
Difficult Child	40.22 (2.31)	23.67(2.53)

In order to examine child characteristics which may contribute to parenting stress, the PSI-SF score was entered as a dependent variable into a regression analysis with the VABS-II total adaptive behavior composite score and the maladaptive behavior composite score as the independent variables. R was .704, R^2=.495 which was statistically significant, F(2,30)=14.89, p<.0001. Beta standardized coefficients for the adaptive behavior composite and maladaptive behavior composite score were, respectively, -.072 (t=-.437, ns) and .659 (t=4.015, p<.0001).

Supplemental Analysis

One additional analysis was done in order to investigate whether children in the ASD group showed significantly fewer socialization skills than children in the TDC group. The VABS-II scores were entered as the dependent variable into an analysis of variance (ANOVA) with the ASD group versus the TDC group as the between-subjects factor and the three VABS-II subscales as the within-subjects factor. The main effect of groups was significant, F (1,31) =28.67, p<.0001, as was the main effect of subscales, F (2,62) =4.98, p<.01; the groups by subscales interaction was not statistically significant, F (2,62) =1.58, p<.22. For the group main effect, the effect size (partial eta squared) was

.480, and observed power was .999. For the subscale main effect, the effect size (partial eta squared) was .354 and observed power was .942.

The overall VABS-II mean and standard deviation for the ASD group was 70.56 (14.11) and for the TDC group was 99.87 (18.72). The overall mean and standard deviation for Communication subscale was 87.39 (23.98), for the Daily Living Skills subscale was 86.91 (20.29), and for the Socialization was 81.64 (22.43). Pair-wise comparisons to examine differences among subscale scores were performed using Tukey's least significant difference at the .05 level of confidence. The two pair-wise comparisons to reach statistical significance were that the mean of the Socialization subscale was lower than both the Daily Living Skills and Communication.

Means and standard deviations for the three subscales for the ASD and TDC groups are broken down by each of the three VABS-II subscales are shown in Table 3.

Table 3. Means and Standard Deviations for ASD and TDC on the VABS-II

Vineland Adaptive Behavior Scale-II Subscales	ASD Group	TDC Group
Communication	73.11(4.30)	104.53(4.71)
Daily Living Skills	75.50(3.80)	100.60(4.20)
Socialization	67.56(3.85)	95.53(4.21)

CHAPTER III

CONCLUSION

Discussion

This study was conducted to examine mothers' parenting stress when caring for a child with autism. Consistent with the hypothesis mothers of children with autism experienced a higher level of stress compared to mothers of typically developing children. These findings are supported by previous research that found that mothers of children with autism experience high overall parenting stress compared with mothers of typically developing children (Phetrasuwan & Miles, 2009). The majority (54%) of mothers in the ASD group reported that they were not employed which supports the findings by Tunali and Power (2002) who reported that mothers of children with autism placed less emphasis on their careers and more emphasis on their parenting role and experienced reduced leisure time.

According to Abidin (1995) the Total Stress score above a 90 indicate that mothers are experiencing clinically significant levels of stress. The ASD group as well as the TDC groups reflects the stresses reported in the areas of personal parental distress, stresses derived from the parent's interaction with the child, and stresses that result from the child's behavioral characteristics. Mothers in the ASD group also reported being more stressed by their child's maladaptive behavior compared to the TDC group.

Higher stress levels in the difficult child (DC) subscale of the PSI-SF suggest that the mothers of a child with autism experience difficulties in managing the child's basic behavior compared to the levels of stress in mothers of typically developing children. It can be concluded that these levels of stress on ASD mothers are triggered by child's behavior. The regression analyses similarly showed that the child's maladaptive behavior as measured by the VABS-II was highly significant source of parental stress (total PSI-SF), while the ASD groups' lower VABS-II adaptive behavior scores contributed little to parental stress.

The Parent-Child Dysfunctional Interaction subscale showed that mothers of children with autism and typically developing children experience feelings that her child is a negative element in the parent's life. However, this source of stress was not as strong as maladaptive behavior their child might present.

One of the components of stress that is associated with Parental Distress (PD) subscale of the PSI-SF is lack of social support. However, the demographic profile of the ASD group showed they had a large number of social support from both family and community sources Most married, well educated and had adequate income. Sepa, Frodi, and Ludvigsson (2204) found that lack of social support is linked to parenting stress. Even with social support our ASD mothers reported significant parental stress.

The majority of the mothers in this study were not employed. This finding is consistent with previous research that shows that choice of jobs was one of the most unfulfilled needs of parents of children with autism (Lin, Tsai, & Chang, 2008). It may be that work could function as respite for ASD mothers, but maladaptive behavior problems

posed by their ASD children required them to sacrifice outside employment to be full-time parents. The majority of mothers in the TDC group were also not employed; this might have been due to the fact that most were college students, and it could be difficult to maintain a job, college, and a child at the same time. PSI-SF overall scores for the TDC mothers was high enough according to Adidin's (1995) norms, to indicate significant parental stress, although the stress was not as high as mothers from the ASD group.

Part of the reason our sample reported high levels of stress on the PSI-SF may have been that mothers rather than fathers, completed the scale. The female gender identity of our U.S. culture prescribes that women are more emotionally expressive than men (Helgesson, 2009). It may be that the mothers in our sample were open in professing their stress, much more than fathers would have been.

Finally, most of our mothers were Hispanic origin. Other studies of parenting stress with ASD children have not included Hispanic populations (Rivers and Stoneman, 2003). Previous research conducted by Hanline and Daley (1992) showed that Hispanic families of children with a disability had well-developed coping resources. But while Hispanic families were found to cope well with the challenges of having a disabled child, Hanline and Daley also found that this social support from friends, relatives, extended family, and neighbors negatively impacted the family's sense of competence. Hanline and Daley's (1992) work suggests that our families may have utilized their coping strategies that were already a part of their lives to adapt and meet the challenges when parenting a child with disabilities. However, if our ASD group mothers experienced a reduce sense of competence as Hanline and Daley's work suggests, this may have been a

contributor to parental stress. Thus the strong social support which may be characteristic of Hispanic families might come at a price of increased stress accompanied by a reduced sense of competence. Additional research is needed to clarify the possible role of being of Hispanic origin on stress incurred in caring for an ASD child.

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APPENDIX A

APPENDIX A

Demographics Questionnaire

1. Age of Mother: _____

2. Age of Father: _____

3. Marital Status:
    a. Single
    b. Married
    c. Living with a partner but not married
    d. Widowed
    e. Divorced

4. Mother's highest education
    a. Some High School
    b. High School Diploma
    c. Some College
    d. Bachelor's degree
    e. Master's degree or higher

5. Father's highest education
    a. Some High School
    b. High School Diploma
    c. Some college
    d. Bachelor's degree
    e. Master's degree or higher

6. Yearly Income:
    a. 10,000-20,000
    b. 20,000-40,000
    c. 40,000-60,000
    d. 60,000 and higher

7. How long have you lived at current residence? _____
8. Do you own or rent your house/apartment? _____

9. Are you currently employed?
    a. Yes
    b. No

10. Location of employment:_____

11. How long have you been employed at this current job?_____

12. Total number of members currently living in your household? _____

13. Number of your children in the household: _____

14. What is the age and sex of your child with autism?_____

15. Has he/she received a diagnosis of autism?_____

16. If yes, by whom was your child diagnosed? (Psychologist, General Practitioner, etc) _____

17. Please list any medications that your child with autism is currently taking.

    _____
    _____

18. Have you been diagnosed with a disability?
    a. Yes
    b. No

19. If yes, what type of disability have you been diagnosed with?

_____

20. From oldest to youngest, please fill out the information below about your other children not including your child with autism.

Age	SEX (M/F)	LIVING WITH YOU? (Y/N)	IS CHILD DIAGNOSED WITH A DISABILITY? (Y/N)	TYPE OF DISABILITY

21. What assistance/resources are available for your children in general? (Please check all that apply.)

Family Help:
_____ Husband
_____ Parents
_____ In-Laws
_____ Grandparents
_____ Brother
_____ Sister
Other family member not mentioned:
_____
_____

Other Resources:
_____Day Care
_____ Parent Support Groups
_____ Respite Care

_____ School
_____ Therapy
Other resources not mentioned:
_____
_____

APPENDIX B

APPENDIX B

Informed Consent

Parenting Stress on Mothers of Children with Autism &

Sibling Stress in Families of Children with Autism

You are being invited to participate in a research study about the comparison on stress on mothers of children with autism and mothers of typically developed children. We are also looking into the stress of siblings of children with Autism. This study is being conducted by Janett Cantu and Valerie Moreno, graduate students, from the College of Social and Behavioral Science at The University of Texas-Pan American.

There are no known risks if you decide to participate in this research study. There are no costs to you for participating in this study. The information you provide will be used to measure the levels of stress on mothers of children with and without autism. The information provided will also help measure the levels of stress on siblings of children with and without autism. The questionnaires will take about 1-2 hours to complete. The information collected may not benefit you directly, but the information learned in this study should provide more general benefits to society.

The questionnaires are anonymous. Please just write your name on the demographics questionnaire and the rest of the questionnaires will be coded so that no one will be able to identify you or your answers, and no one will know whether or not you participated in the study. Should the data be published, no individual information will be disclosed.

Your participation in this study is voluntary; you may discontinue your participation at any time without penalty. If for any reason you decide that you would like to discontinue your participation, simply tell the researcher that you wish to stop. By completing the demographics questionnaire, Parenting Stress Index-Short Form, Vineland Adaptive Behavior Scale-II, and the Strengths and Difficulties Questionnaire, you will seal it in an envelope that will be provided to you and put it inside a box that will be placed in the room, you are voluntarily agreeing to participate. You are free to decline to answer any particular question you do not wish to answer for any reason.

The researcher will provide you with a copy of this form for your own reference. In order to participate, you must be at least 18 years of age. If you are under 18, please inform the researcher

. If you have any questions about the study, please contact the researchers, Janett Cantu at 956-802-1188 or at jccantu_1707@yahoo.com and Valerie Moreno at 956-827-3005 or at Valerienmoreno@gmail.com. You may also contact our advisor, Dr. Gary T. Montgomery at (956) 381-2967.

If you have any questions about your rights as a participant, or if you feel that your rights as a participant were not adequately met by the researcher, contact the Institutional Review Board for Human Subjects Protection at 956-381-3002 or irb@utpa.edu.

APPENDIX C

APPENDIX C

Recruitment for Graduate Thesis Study

You are being invited to participate in a research study about the comparison on stress on mothers of children with autism and mothers of typically developed children. We are also looking into the stress of siblings of children with Autism. This study is being conducted as part of our graduate thesis requirements under the supervision of Dr. Gary T. Montgomery from the University of Texas-Pan American.

In order to participate, you must:

1. Be at least 18 years old.

2. Be able to read and speak English.

3. Have a child with autism and at least one other child that has not been diagnosed with Autism.

4. Be able to attend a research session, held at the First United Methodist Church, during which you will be asked to complete a number of questionnaires. The questionnaires include demographic questions (such as age and education) along with specific measures related to parenting stress and the behavior of both your child with autism and child without autism. The session will take between 1-2 hours.

The research session dates and times have yet to be finalized. If you think you are interested in participating, please contact either **Valerie Moreno @ 956-827-3005 Valerienmoreno@gmail.com** or you may contact **Janett Cantu @ 956-802-1188 janettcantu24@gmail.com.**

APPENDIX D

APPENDIX D

Recruitment for Graduate Thesis Study

You are being invited to participate in a research study about the comparison on stress on mothers of children with autism and mothers of typically developed children. We are also looking into the stress of siblings of children with Autism. This study is being conducted as part of our graduate thesis requirements under the supervision of Dr. Gary T. Montgomery from the University of Texas-Pan American.

In order to participate, you must:

1. Be at least 18 years old.

2. Be able to read and speak English.

3. Have at least two children who have not been diagnosed with Autism.

4. Be able to attend a research session, held in a room in the UTPA Social & Behavioral Sciences Building, during which you will be asked to complete a number of questionnaires. The questionnaires include demographic questions (such as age and education) along with specific measures related to parenting stress and the behavior of both your child with autism and child without autism. The session will take between 1-2 hours.

The research session dates and times have yet to be finalized. If you think you are interested in participating, please contact either Valerie Moreno @ 956-827-3005Valerienmoreno@gmail.com or you may contact Janett Cantu @ 956-802-1188 janettcantu24@gmail.com.

BIOGRAPHICAL SKETCH

Janett Cantu is the daughter of Mr. and Mrs. Jose and Juanita Cantu and the wife of Mr. Albert Sanchez. She is also the mother of a son, Alan Alberto Sanchez. She is the second of four children. She is of a family who worked very hard and migrated north to work in the fields, which continued up to high school. She received an Associate Degree in Elementary Education and continued working towards the Bachelor's in Psychology which she got in May 2007. After graduation she in 2007 the following year in the fall of 2008 she starting her Master's degree in Experimental Psychology with a concentration in Applied Behavior Analysis in August of 2008.

Janett looks forward to taking the BCBA certification exam in September 2010. She plan on working in this field and helping children with autism in the Rio Grande Valley.