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SIBLING STRESS IN FAMILIES OF CHILDREN WITH AUTISM

A Thesis

by

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Submitted to the Graduate School of the
University of Texas-Pan American
In partial fulfillment of the requirements for the degree of

MASTER OF ARTS

May 2010

Major Subject: Psychology

SIBLING STRESS IN FAMILIES OF CHILDREN WITH AUTISM

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May 2010

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ABSTRACT

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Siblings of children with an autism spectrum disorder (ASD) may have an increased chance of experiencing more stress than siblings of typically developing children. Stress experienced by siblings of children with an ASD may be dependent on the adaptive and maladaptive behavior of the child with autism. A total of 30 mothers were recruited in this study. Results indicated that the difference in stress levels in siblings of children with an ASD and siblings of typically developing children were not statistically significant. It was also found that the stress levels in siblings of children with an ASD were not dependent on the adaptive or maladaptive behavior of the child with an ASD.

DEDICATION

The completion of my masters studies would not have been possible without the love and support of my family. My husband, Robert Neeley, my mother, Linda Moreno, my father, Ricardo Moreno Jr., and my sister, Monica Mata, who were always there to motivate and support me wholeheartedly by all means to accomplish this degree. Also, to Dr. Frederick Ernst who started the BCBA concentration in Experimental Psychology and who always encouraged me to be stay positive even when things went wrong. Thank you all for your love and patience.

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CHAPTER I

REVIEW OF LITERATURE

Overview of Autism

Autism spectrum disorders (ASD) encompass many labeled disorders such as autism, pervasive developmental disorders, and Asperger syndrome. Autism includes pervasive impairments across multiple domains of development and are generally lifelong disabilities for the majority of affected individuals (Shattuck, Seltzer, Greenberg, Orsmond, et al., 2007). Symptoms of this psychological disorder typically include varying levels of impairment in interpersonal skills, emotional or affective behavior, and intellectual functioning. Children with autism are frequently unresponsive to others, fail to make eye contact, and miss social cues such as a person's facial, verbal, postural, and gestural responses (Schoen, 2003).

Children with autism often develop disturbing behaviors that may include atypical eating, abnormal sleep patterns, self-injurious behavior, aggression, and temper tantrums. The most common atypical eating behavior may be excessive food selectivity by type and texture of the food. Abnormal sleep patterns are more common in younger children with autism and are associated with self-injury, aggression, screaming, tantrums, noncompliance, and impulsivity. The most commonly reported problems by parents

include difficulty falling asleep, frequent awakenings throughout the night and early morning awakenings. Self injurious behavior has been associated with lack of receptive and expressive communication in children with autism. Temper tantrums are most common in young children with autism and decrease in frequency with age (Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007).

Individuals with autism, mental retardation, and pervasive developmental disorder engage in maladaptive behaviors that can be dangerous to themselves or others.

Maladaptive behaviors interfere with everyday activities, and include self-injurious behavior, withdrawal, uncooperative behavior, aggression, and destruction of property (Shattuck, et al., 2007). These behaviors may also impede their learning and daily living skills. The problems that have received the most attention in these populations are self-injurious behavior (SIB), aggression/noncompliance, and stereotyped behaviors. SIB is considered to be one of the most dangerous problems for persons with mental retardation and other developmental disabilities (Dawson, Matson, & Cherry, 1998). Self-injury is a bizarre and often chronic form of aberrant behavior, the etiology of which is poorly understood. It poses serious risks to those who engage in the behavior, and it represents a formidable challenge to those who are responsible for treating it (Iwata, Dorsey, Slifer, Bauman, & Richman, 1994).

One of the most pervasive characteristics of autism is a delay or impairment in the ability to produce and respond to language. Many children with autism do not develop speech and other children with the disorder often exhibit unusual speech patterns such as echolalia or the repetition of what has been heard (Schoen, 2003). With this lack of availability to communicate verbally, individuals with autism might rely on inappropriate

behavior, such as aggression, to achieve functional effects normally produced with speech (Barry, & Singer, 2001).

In addition, children with autism display many abnormal behaviors that cause serious distress for both the child and the family. Unusual eating habits, abnormal sleep patterns, temper tantrums, and aggression to self and to others are among the most common of these abnormal behaviors. In children with autism, lower levels of expressive functional language and more severe scores on the communication, socialization and daily living skills domains of the Vineland Adaptive Behavior Scales are associated with increased self-injury. In children with autism and mental retardation, aggression is related to gender, age, and expressive communication. Of the studies that have been done in this area, research suggests that among children with mental retardation, a diagnosis of autism is associated with a higher incidence of tantrums, aggression, and destruction of property (Dominick, Davis, Lainhart, Tager-Flusberg & Folstein, 2007). These odd behaviors displayed in children with autism are a few of the many characteristics that can make public contact and family outings challenging for parents and siblings of children with autism (Kaminsky & Dewey, 2002).

The greater complexity, unpredictability, and inexplicability of autism place the family at a greater risk for poor psychological adjustment. Macks and Reeve (2007) found that there is more stress in families of children with autism than in families with children who have other disabilities. There is a greater disruption of family functioning, more upset, and disappointment about the child with a handicap, and fewer recreational activities and vocational possibilities. The diagnosis of any disorder within a family member is a powerful event for the whole family in many ways that are difficult to

predict (Schuntermann, 2007). The impairments of autism are thought to last a lifetime and continue to pose challenges for the affected individual and his or her family (Selzter, Shattuck, Abbeduto, & Greenberg, 2004). With the growing number of children who receive a diagnosis of ASD and with better prognosis associated with early detection and intervention, researchers are currently focusing on efforts on the identification of early markers for autism related conditions. Various methodologies are being employed to diagnose autism and autism related difficulties at the youngest possible age (Gamliel, Yirmiya, & Sigman, 2007).

Importance of Sibling Relationships

Among all human relationships, sibling relationships typically last over the lifespan. Nurturance and conflict in the sibling relationship provide siblings with experiences that foster the development of emotional understanding, self-regulation, and a sense of belonging and comfort. Sibling interactions are essential and powerful components of socialization because they foster the development of important instrumental and affective relationship skills. What is learned from relating to siblings can potentially influence cognitive, affective, and social skills as well as the development of a positive self image. Positive and frequent sibling interactions provide important sources of emotional support, whereas negative and infrequent sibling interactions may disrupt the psychological adaptation process. Siblings begin as play partners and sources of support through intimate daily contact during childhood. Overall, girls tend to report more affection and intimacy in their sibling relationships than boys, although the sex constellation might also make a difference (Orsmond & Seltzer, 2007; Rodrigue, Geffken

& Morgan, 1993). The sex of the non-disabled sibling seems to be central to his or her experience with the disabled child, particularly when sex is considered together with the non-disabled sibling's birth order and the socioeconomic status of the family. Also, poorer sibling adjustment is more common with increased severity of the disability (Gold, 1993). Positive relationships among siblings can be an important source of social support for children and are associated with lower levels of conduct disorder and loneliness in children and higher self-worth (Kaminsky & Dewey, 2001).

Autism Diagnosis and Positive Impacts on Sibling Relationships

Families use a variety of coping strategies when dealing with stress. Access to social support has been related to positive family and child outcomes in families of children with a variety of disabilities. Rivers and Stoneman (2003) conducted a study in this area and results indicated that typically developing siblings in general, were quite positive in their ratings of their relationship with their siblings with autism. There were no significant correlations between the sibling measures and the demographic characteristics of participants. These demographic characteristics included age of typically developing sibling, sibling age spacing, maternal age, mother's or father's education, family income, number of children in the family, severity of autism in the sibling. The only significant correlation was between the age of the child with autism and the typically developing sibling's rating of satisfaction with the sibling relationship.

Some other positive findings of outcomes for siblings of children with autism have reported less conflict and greater warmth in the sibling relationship than siblings of typically-developing children. Siblings have been found to be important social agents for

children with autism, who make more vocal and verbal initiations towards their siblings than towards their parents. Typically developing siblings have reported being proud of their ability to “teach” their younger siblings with autism (Rivers & Stoneman, 2003).

Verte, Roeyers, and Buysse (2003) found that sisters of children with autism had higher social competence than sisters of the normative sample. Sisters of children with autism between the ages of 12 and 16 years old also had a more positive self-concept than sisters of the normative sample.

Pilowsky, Yirmiya, Doppelt, Gross-Tsur, and Shalev (2004) conducted a study on social and emotional adjustment of siblings of children with autism. Their findings indicated that socialization skills and behavior problems for siblings of children with autism were found to be well functioning based on normative data. This finding along with previous research, suggests that most of the siblings of children with autism are reasonably well adjusted.

Autism Diagnosis and Negative Impacts on Sibling Relationships

Having a sibling with a disability can impact the family directly with stress that is generated directly by the child with the disability. Stress can also affect the family indirectly through the disabled child’s impact on parental and marital functioning. This parental and marital stress can then lead to chronic emotional and behavioral problems in non-disabled siblings. Siblings of chronically ill or mentally disabled children have also been found to be at risk for externalizing and internalizing problems (Fisman, Wolf, Ellison, & Freeman, 2000). Typically developing siblings of children with autism have

reported that they are disturbed sometimes by their siblings' behaviors (Rivers & Stoneman, 2003).

Having a family member with any illness, handicap, or disability might be challenging, and the combination of impairments associated with autism might place family members at an especially high risk for psychological difficulties (Macks & Reeve, 2007). Bagenholm and Gillberg (1991) showed results that indicated that siblings of children with autism were somewhat more negative in their views concerning their sibling relationship than siblings of mentally retarded and healthy children. Also, siblings of children with autism reported that they felt lonely when compared to siblings of typically developing children.

Gold (1993) mentioned how unusual expectations and responsibilities imposed on siblings for caregiving or domestic work increase the likelihood of role strain and problems in both social and academic adjustment in siblings of children with disabilities. Gold showed in his study that younger brothers of disabled children had more psychological impairment than older brothers, but older sisters showed more impairment than younger ones. It was found that those less than 2 years younger than the disabled child had greater adjustment difficulties than those more than 2 years younger. Siblings in larger families seem to adjust better than siblings in smaller ones. However, this finding is inconsistent with Pilowsky, Yirmiya, Doppelt, et al. (2004) that found that the larger the family size, the greater the delay in sibling's socialization skills. Siblings, also to a large extent, echo and identify with their parents' feelings and attitudes, and parental shame, guilt, anxiety, or acceptance may be more critical influences on the sibling than the objective characteristics of the disabled child (Gold, 1993).

Verte, Roeyers, and Buysse (2003) looked at whether having a brother or sister with autism was associated with a disadvantage or a benefit for the siblings in three domains of psychological adjustment. These included behavioral problems, social competence, and self-concept. Parents of children with autism reported more behavioral problems for their other children than parents of children without a diagnosed disorder.

Rivers and Stoneman (2003) found other negative outcomes in siblings of children with autism, including loneliness and reports of hassles with their atypical siblings' behavior, externalizing and internalizing behavior problems, depression, and sibling interactions that were less socially reciprocal. Some externalizing behaviors that siblings have problems with can include limited family interactions because they choose not to participate in socializing with the family. Internalizing problems in siblings of children with autism include the child feeling more isolated and lonely than other siblings of typical children. The fact that the relationship between siblings of children with autism are less socially reciprocal places more stress on the typical developing sibling because the atypical sibling cannot communicate properly to their sibling (Orsmond, Kuo, & Seltzer, 2009).

Children with autism and their siblings have been found to spend less time together than typically-developing siblings or siblings of children with Down Syndrome (Rivers & Stoneman, 2003). Giallo and Gavidia-Payne (2006) conducted a study that illustrated that siblings had significantly lower ratings when it came to prosocial behavior compared with the normative data, (e.g. helping others without them asking for help). It also was revealed that the relationship between social economic status (SES) and

adjustment difficulties was mediated by parent stress and family resilience factors. Thus, although SES is related to adjustment, family factors also play an important role.

Siblings of children with autism may be less likely to report high levels of prosocial behavior, intimacy, and nurturance by their sibling, because of the variety of social deficits related to autism. Children with autism may be rated as less nurturing by their siblings because they often have deficits in understanding other's perspectives and tend to be unresponsive to other's emotions. Limitations in cognitive functioning may further impede children with autism from assisting and attending to their normally developing sibling. Children with autism have deficits such as lack of reciprocity in conversation, or an overall lack of speech, which likely inhibit intimate interchanges with siblings such as sharing thoughts and feelings (Kaminsky & Dewey, 2001). Researchers have also found that while the majority of siblings are well adjusted, there are a small number of siblings that are at risk of developing more peer problems, lower levels of prosocial behavior, and more overall adjustment problems. Some of these adjustment difficulties pertain specifically to their sibling's aggressive behaviors and syndrome-specific behaviors (Hastings, 2003; Ross & Cuskelly, 2006).

Orsmond and Seltzer (2009) conducted a recent study on adolescent siblings of individuals with an autism spectrum disorder. Their main finding was that brothers in the sample did not report heightened depressive and anxiety symptoms like previous literature has stated. Sisters, on the other hand, did report higher levels of depressive and anxiety symptoms than brothers. Having a family history of ASD's was associated with more depressive, but not anxiety symptoms. A high level of maternal depressive

symptoms was also associated with both more depressive and anxiety symptoms in her children.

Orsmond, Kuo, and Seltzer (2009) found that the behavior problems in the child with autism negatively impacts the sibling relationship. Behavior problems of the child with ASD may make siblings less willing to engage in activities with their brother or sister, especially in activities that occur in the public area. Difficult behaviors may also indirectly influence sibling activities, as parents may be less willing to engage in family activities such as going out to a restaurant and therefore limiting the opportunity for siblings to engage in shared activities.

Petalas, Hastings, Nash, Lloyd, and Dowey (2009) compared siblings of children with an intellectual disability (ID) with and without an additional diagnosis of autism on a standardized measure of behavioral and emotional adjustment. The study also compared the siblings of children with autism to a larger normative sample. They collected data on the stability of psychological problems in siblings of children with autism over an 18 month period and explored correlates of emotional and behavioral adjustment for the siblings of children with autism. It was found that siblings with a brother with autism and ID had higher emotional problem scores than those with a sister with autism and ID. Siblings younger than the child with autism and ID had higher emotional problem scores than those who were older than the child with autism and ID. Interactions with one's siblings provide opportunities for experiencing and expressing many emotions.

Proposed Study

Sibling relationships help children practice certain skills such as self control, sharing, listening, conflict resolution, and fair play. Given the importance of experiences within the sibling subsystem, it is essential that we increase our understanding of the impact on children of possible disturbances within this subsystem (Ross & Cuskelly, 2006).

Hypothesis I

The primary objective of this proposed study is to determine whether siblings of children with autism display more emotional or behavioral problems than siblings of typically developing children. The first hypothesis is that more emotional and behavioral problems will be revealed in children with siblings who have been diagnosed with autism. Stated in the null, my statistical analysis will test the hypothesis that there is no difference in emotional or behavioral problems between children who have a sibling with autism and those who do not have a sibling with autism.

Hypothesis II

The second hypothesis is that the total amount of stress experienced within the typically developing sibling will also depend on the level of adaptive behavior and maladaptive behavior in the child with autism. Therefore, the null hypothesis here is that there is no relationship between reported stress levels of the typical developing siblings and the adaptive level and maladaptive level of the child with autism.

CHAPTER II

METHODOLOGY AND FINDINGS

Participants

A total of thirty mothers were recruited to participate in this study. Fifteen mothers were in the autism spectrum disorder group (ASD) and the other fifteen mothers were a part of the typically developing children group (TDC). This study included one African American, two White, and 27 of the participants were Hispanic. Other demographic characteristics of participants are summarized on Table 1. The participants were recruited within a radius of about 20 miles of a large metropolitan statistical area near the Mexican border in South Texas.

ASD Group

Fifteen mothers that were recruited had at least one typically developing child and a child with an autism spectrum disorder. Out of the thirteen families who disclosed age of diagnosis, the age range was 2-6 years and the median age was 4 years old. Thirteen mothers in the ASD group that reported the diagnosis code of their child were as follows: 4 were reported to be diagnosed with an Autistic Disorder, 3 reported to have Asperger's Disorder, and 6 reported that their child was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified.

TDC Group

A comparison group of fifteen mothers who had at least two typically developing children closely matched in age with the ASD group were recruited. The children of mothers in the comparison group had not received a diagnosis of an ASD.

Table 1. Other Demographic Variable

	ASD	TDC		ASD	TDC
Mother's Age	24-45	23-45	Own or Rent Home		
Median Age of Mothers	35	34.5	Own	12	11
Marital Status			Rent	3	4
Single	1	2	Employment		
Married	11	10	Yes	6	4
Living with partner	1	2	No	9	11
Divorced	2	1	Number of Family Resources		
Mother's Education			0	1	2
Some High School	1	0	1-2	5	3
High School Diploma	2	2	3-4	7	7
Some College	9	10	5-6	1	1
Bachelor's Degree	2	1	7-8	1	2
Master's Degree or higher	1	2	Number of Community Resources		
Father's Education			0	0	2
Some High School	1	4	1-2	8	13
High School Diploma	2	4	3-4	7	0
Some College	4	3			
Bachelor's Degree	6	3			
Master's Degree or higher	2	1			
Annual Income					
10,000-20,000	1	2			
20,000-40,000	7	3			
40,000-60,000	4	5			
60,000-higher	3	5			

Measures

A demographics questionnaire (see Appendix A) was used to collect the basic background information about the participants in the ASD group and the TDC group which will be referred to in the “Participants” section. Mothers in the ASD group completed the Vineland Adaptive Behavior Scale-II (VABS-II) Parent/Caregiver Rating Form, which was used to assess the adaptive behavior of the child with autism. The VABS-II was a 383 item survey form used to assess four main domains which included: communication, daily living skills, socialization, and motor skills. The VABS-II also included an index that measured maladaptive behavior of the child with autism. This measure took about 20-60 minutes to complete (Sparrow, Cicchetti, & Balla, 2009).

Mothers also completed the Strengths and Difficulties Questionnaire (SDQ; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009) that asked questions about the typically developing sibling. This was a 25 item behavioral screening measure that took about 10-15 minutes to complete. The SDQ measured four problem areas that assessed emotional problems, conduct problems, hyperactivity, and peer relationship problems. The SDQ provided a total difficulties score that was composited by summing the scores from each of the four problem domains.

Procedure

Verbal and email recruitments were made for the ASD group through a local autism support group (see Appendix B). The TDC group was also recruited verbally and through email at a local university and through the autism support group (see Appendix C). Once participants contacted the researcher, scheduled appointments were made.

Questionnaires were administered at convenient locations for participants, including location of support group meetings and at the local University. Each participant was given a packet that included an informed consent (see Appendix D), the demographics questionnaire, the VABS-II, and the SDQ. To insure complete privacy of identity for each participant, each packet contained no personally identifying information but was differentiated only by a number assigned as participants turned in their forms.

ASD Group

Once the informed consent was read by the participant, the demographics questionnaire was completed. Then the mothers were asked to complete the SDQ questionnaire regarding the typically developing sibling that was closest in age to their child with autism. The VABS-II questionnaire was then completed by the mother about the child with autism.

TDC Group

After the informed consent was read by the mothers, the demographics questionnaire was completed. The mothers were then asked to complete the SDQ questionnaire about the sibling that was closest in age to the normally-developing sibling in the ASD group. Next, the VABS-II was given to the mother to complete about their typically developing child that was closest in age to the child with autism in the ASD group. Before the participants turned in their packet of questionnaires, the researcher checked over each questionnaire to make sure that the participants did not skip over any

sections. 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 SDQ total difficulties score was 11.17 (6.84). Chronbach's alpha coefficients for the total sample of children with ASD and typically developing children in the TDC group were as follows: .99 for total adaptive behavior composite score and .91 for total maladaptive behavior index score.

To test whether the distribution of the SDQ total difficulties scores within the two groups deviated from normal, and to determine whether there was a floor effect, skewness and kurtosis values were examined. The skewness value of .56 and kurtosis value of -.72 indicated that the scores were positively skewed and platykurtic meaning that scores were more spread-out in shape compared with a normal distribution. A one-sample Kolmogorov-Smirnov (K-S) Test was conducted to validate the assumption of normality. The results indicated $K-S=.887, (p>.05)$ that the data were indeed normal, thereby allowing for the use of a one-way ANOVA.

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 means that this sample was performing at an adequate level and fell within the 21st percentile rank with the normative sample. Chronbach's alpha coefficients for the total sample of children with ASD and typically developing children in the TDC group were as follows: .99 for total adaptive behavior composite score and .91 for total maladaptive behavior index

score. The skewness value of .87 and the kurtosis value of 1.53 indicated that the scores were positively skewed and leptokurtic meaning that scores were less spread-out in shape compared with a normal distribution. One-sample K-S Test for the adaptive behavior composite score was $K-S=.506, (p>.05)$. The mean and standard deviation of the Maladaptive Behavior Index Score was 17.97(4.17). A score between 1 and 17 means that the child is at 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. The K-S Test for the maladaptive behavior index score revealed that $K-S=.763, (p>.05)$.

Statistical Comparisons

To test whether siblings of autistic children experience more coping difficulties than siblings of normally-developing children, the SDQ total difficulties score was entered as the dependent variable into a one-way analysis of variance (ANOVA) to compare the stress of siblings in the ASD group versus the TDC group. The results of the one-way ANOVA were not statistically significant, $F(1,28)=.03, p > 0.05$.

The mean and standard deviation of the SDQ total difficulties score for siblings in the ASD group was 10.93 (5.8) compared to the mean and standard deviation of 11.40 (7.9) for siblings in the TDC group. The effect size (partial eta squared) was .001 and the estimated power was .054. Because the skewness and kurtosis showed that the distribution of SDQ total difficulties scores departed from normality, a Mann-Whitney U non-parametric test was used to examine differences in SDQ total difficulties scores.

There were no statistically significant differences between the ASD group and the TDC group on the SDQ total difficulties score ($U=99, p=.57$).

To test whether siblings experience more coping difficulties if their autistic sibling presents low levels of adaptive behavior and high number of behavior difficulties, the SDQ total difficulties score was entered as a dependent variable into a regression analysis with the total adaptive behavior composite score and the maladaptive behavior index scores from the VABS-II as the independent variables. R was .10, $R^2=.01$ which was not statistically significant.

Supplemental Analysis

To investigate whether there were differences in the adaptive behavior composite score and the maladaptive behavior composite score between the two groups, a Mann-Whitney U non-parametric test was used. There were statistically significant differences between the ASD group and the TDC group in the adaptive behavior composite score ($U=21.5, p=.001$) and the maladaptive behavior composite score ($U=25.5, p=.001$) of the VABS-II. The mean and (standard deviation) of the adaptive behavior composite scores for the TDC group was 99.87(18.72) and 71.2(15.2) for the ASD group. The mean and (standard deviation) of the maladaptive behavior index scores for the TDC group was 15.07(1.38) and 20.60(1.84) for the ASD group.

CHAPTER III

CONCLUSION

Discussion

The analysis of SDQ total difficulties score failed to demonstrate a statistically significant difference between stress in siblings of children with autism and siblings of typically developing children as reported by the mothers. Therefore, we failed to reject the null hypothesis. These findings were not similar to previous literature. Results may have been inconsistent because of the smaller sample size although Petalas et. al (2009) had a small sample size of 24 participants and they found statistically significant differences between their two groups of children with an ID and autism versus children with only an ID.

However, it was interesting to find that the SDQ total difficulties means were high in both the TDC and the ASD group when compared to a normative sample. This indicates that the parents' rating of their typically developing child was actually higher than the normal sample; a high score indicates greater difficulties in coping. Goodman (1997) found that the National Health Interview Survey (NHIS) included the SDQ in the 2001 NHIS Supplement survey from a sample of 9,878 families with children between

the ages of 4 and 17 years old. The results showed that the majority of children scored between 2 and 6 in the total difficulties score. This elevated score in the SDQ might be because the current sample was predominantly Hispanic in ethnicity when compared to previous literature where White seems to be the predominant ethnicity.

Following a regression analysis of SDQ total difficulties score and adaptive behavior composite score and maladaptive behavior composite score between the ASD group and TDC group, the results indicated no statistically significant difference. SDQ total difficulties score of siblings in the ASD group were not dependent on the adaptive behavior composite score or the maladaptive behavior composite score of the child with autism. However, supplemental analyses showed that there were statistically significant differences in the adaptive behavior composite scores and the maladaptive behavior composite scores between the ASD group and the TDC group; this shows that children diagnosed with an ASD have lower adaptive behavior and higher maladaptive behavior when compared to typically developing children. These results indicate that siblings in the ASD show resilience towards the child with autism and are equivalent in their level of coping skills with children in the TDC group.

Perhaps these results were inconsistent with previous literature because the majority of the sample were highly educated, married, had a large number of community and family resources, and were predominantly Hispanic. This strong support system for the mothers of children with autism relates to the literature that families who remain close, confident and optimistic about their ability to manage stressful times tend to employ effective coping strategies (Giallo & Gavidia-Payne, 2006). The marital status, employment status, and income levels in this study were similar to previous studies

which stated that the majority of the mothers with a child with autism were married and not working. Mothers in this category also had similar income levels between \$20,000 to \$60,000 and the majority of their education level fell within the "some college" range (Giallo & Gavidia-Payne, 2006; Macks & Reeve, 2007; Petalas et al., 2009). One interesting finding from Rivers and Stonemann (2003) was that most families in their study reported to be Euro-American. They only had one participant report to be Hispanic which is different when compared to this study where the majority of participants were of Hispanic ethnicity.

Hanline and Daley (1992) conducted a study comparing Hispanic, African-American, and Caucasian families of young children. This study showed that Hispanic families of children with a disability had well-developed coping resources. 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. Hispanic families in this study acquired social support from relatives, friends, extended family, and neighbors which negatively impacted the family's sense of competence. This acquired social support helped the Hispanic families to engage in behaviors that had a positive effect on family functioning.

Further research should expand on this area of research to explore the Hispanic community and the levels of stress in siblings of children with autism. This study should be replicated with the Hispanic population in a different geographic region to find out if these elevated levels in SDQ total difficulties scores pertain to other regions in the nation.

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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 an autistic spectrum disorder? _____
- a. If yes, at what age was your child diagnosed? _____
 - b. If yes, by whom was your child diagnosed? (Psychologist, General Practitioner, Psychiatrist, etc) _____
 - c. If yes, which of the following did the doctor diagnose?
 - i. Autistic disorder _____
 - ii. Rett's disorder _____
 - iii. Childhood disintegrative disorder _____
 - iv. Asperger's disorder _____
 - v. Pervasive developmental disorder _____
(or Pervasive developmental disorder NOS which means "not otherwise specified")

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

17. Have you been diagnosed with a disability?

- a. Yes
- b. No

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

19. 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

20. 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

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 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 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 @ 956-827-3005** **Valerienmoreno@gmail.com** or you may contact **Janett Cantu @ 956-802-1188** **janettcantu24@gmail.com**.

APPENDIX D

APPENDIX D

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.

BIOGRAPHICAL SKETCH

Valerie Nicole Moreno is the youngest daughter of Rick and Linda Moreno and the wife of Robert K. Neeley. She received her Bachelor's of Arts in Psychology at the University of Texas-Pan American and graduated top of her class in December 2008. She then worked for a therapy company for one year and then started the masters program in Experimental Psychology with a concentration in Applied Behavior Analysis in August 2008. During this time she worked as a research assistant for the BCBA practicum, along with completing her practicum hours, and working as an assistant manager at a local DME.

Valerie looks forward to taking her certification exam in September 2010 so that she can become a board certified behavior analyst. She plans to continue working in the health care field and helping children with autism.