THE RELATIONSHIP BETWEEN PARENTAL STRESS, AUTISM SEVERITY, AND COMMUNICATION ABILITY

An Undergraduate Research Scholars Thesis

By

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TABLE OF CONTENTS

ABSTRACT

The Relationship Between Parental Stress, Autism Severity, and Communication Ability.
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When compared with various types of developmental disabilities, both physical and intellectual, autism has consistently shown a great number of problem behaviors and lower scores of maternal well-being (Blacher and McIntyre, 2006). The current study ought to examine whether autism severity and/or child social communication were related to parental stress levels. In addition, we examined whether levels of parental stress were associated with higher levels of drinking behavior. Though no significant association was found between autism severity or social communication and parental stress (possibly due to s mall sample size), correlations between social communication as well as the ATEC Speech and Sociability subscales and parental stress levels approached significance.

DEDICATION

Without my experiences during my seven years at Camp Children's Association for Maximum Potential, I would not have had the inspiration for the current study. I would like to recognize and thank all of those who are caregivers for a child with autism, especially those who were willing to take part in this study, as it takes an incredibly special person to care for someone with ASD.

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CHAPTER I

INTRODUCTION

According to recent data, the estimated prevalence of autism is 1 in 88 children, representing a steady increase in recent years (Autism Developmental Disabilities Monitoring Network, 2012). Clinical manifestations across the autism spectrum vary greatly, and 75% of children diagnosed with autism will require parental or societal support across the lifespan (Miles, McCathren, Stichter, & Shinawi, 2003). Therefore, a greater understanding of parental stress due to autism could be used to improve the lives of parents and caregivers of children with autism. Although significantly higher levels of stress in mothers of children with autism have been found when compared with normal controls and other disabilities (Blacher &McIntyre, 2006), it is not clear which aspects of autism contribute to increased level of stress. In a nine month study by Osborne and Reed (2010), parental stress increased with less self-perceived involvement and poorer communication with children across the autism spectrum.

The diagnosis of autism changed in May 2013 with the revisions made for the DSM-5. These changes include the removal of Asperger's Disorder and Pervasive Developmental Disorder-Not Otherwise Specified distinctions, as well as an increase in the number of symptoms required in order to meet criteria for a diagnosis of Autism diagnosis (Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012). A study of these revisions on diagnosis indicated that some participants who previously met criteria for diagnosis would not meet the criteria for diagnosis under the DSM-5 revisions, (Gibbs et. al., 2012). These discrepancies in the diagnosis of autism

may indicate that older studies may not be as easily generalized to those diagnosed in the future, thus more research is necessary.

The current study assesses problem behaviors and communication difficulties as reported by caregivers of children diagnosed with autism. According to a stress model developed for assessing negative outcomes for couples raising a child with autism, it is important to investigate characteristics of the relationship between parents and children diagnosed with autism, including the role of child characteristics, parent resources, and forms of social support (Bluth, Roberson, Billen, & Sams, 2013). Bluth's model addresses limitations of previous models of the impact of stress in parents of children with developmental disabilities, and included in this model is the addition of the potential impact of of specific child characteristics that may be present in those with autism spectrum disorder (Bluth et.al., 2013; Perry, 2004). To improve generalizabilty of their proposed model, Bluth suggests that future research elaborate upon various components of the model, especially child characteristics (Bluth, et. al, 2013). Through the use of two distinct measures of parental perception, one concerning autism severity and the other communication ability, the current study aims to more closely examine the "individual child characteristics" component of Bluth's model.

Though there are several proposed models involving the physiological systems that are activated by stress, it is clear that stress has negative effects on the body, such as increased risk of cardiovascular disease, diabetes, hypertension, and obesity, as well as an increased level of pro-inflammatory cytokines (McEwen, 1998), (Cohen et. al, 2012). Although previous research has confirmed that parenting a child with ASD is more associated with maternal stress than raising a

child with another type of physical or mental disability, it remains unclear as to what aspects of the disorder contribute to elevated stress levels (Blacher & McIntyre, 2006). A longitudinal study examining self-reported parenting behaviors and parental stress levels of parents raising a child with autism over 9-10 months found few differences between the parenting behaviors of parents of children with autism compared with controls, yet the stress levels for parents with a child with autism were significantly higher than those of controls (Osborne &Reed, 2010). The results of the study indicate a possible bi-directional interaction between parent stress and the perception of parenting behavior, which includes three dimensions: the parent's involvement with the child, the ability to communicate with the child, and the ability to establish limits with the child (Osborne & Reed, 2010). These findings are consistent with other studies that have shown that social interaction deficits of a child with autism predict maternal stress levels (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Duarte, Border, Yazigi, & Mooney, 2005). However, at this time, it is still unclear which aspects of the deficits in social interaction for those with autism contribute to parental stress (Baker-Ericzen, Brookman-Frazee, &Stahmer, 2005).

The damaging effects of stress are well-known, especially for those under chronic stress, and these effects may be exacerbated by increased use of maladaptive coping mechanisms such as alcohol and tobacco (McEwen, 1998). In a previous study, alcoholism patterns were identified in 39% of family pedigrees obtained through a child with autism, and children with autism in families with a history of alcoholism more likely to experience language loss (Miles, Takahashi, Haber, & Hadden, 2003). Parents may also be more likely to engage in increased drinking when

exposed to children displaying deviant behaviors (Pelham et. al., 1997). Therefore, caregivers of children with autism may exhibit drinking behaviors at a higher rate than the general population.

The present study aims to expand upon the limited research investigating the relationship between reported levels of parent stress among caregivers of children diagnosed with autism and individual characteristics of the child. Specifically, this study compares self-reported parental stress levels with the parents' evaluation of his or her child's communication abilities and autism severity. It is hypothesized that greater deficits in communication by the child will have a stronger positive correlation with parental stress than autism symptom severity. Furthermore, it is hypothesized that higher parental stress levels will predict drinking behaviors of the caregiver.

CHAPTER II

METHOD

Participants

Respondents that qualified for this study were adults who identified themselves as a parent, grandparent, caregiver, or other living in a household with at least one child diagnosed with Autism Spectrum Disorder (ASD). Participants were recruited through fliers and emails sent to various autism family support groups located across the country, primarily focused on the central region of Texas. Participation in this study was voluntary, and the participants did not receive compensation for completing the survey.

Materials

The Autism Treatment and Evaluation Checklist (ATEC)

This measurement of autism places autism on a spectrum of severity, similar to the current projections of autism diagnosis in the DSM-V. The results of the ATEC have a significant correlation with the results of the Childhood Autism Rating Scale (CARS), and the ATEC is able to be completed by parents (Geier, Kern, & Geier, 2013). Additionally, the ATEC has been validated in other languages and countries, such as Iran (Memari et. al., 2013). There is also evidence that the ATEC may a useful measure for monitoring the progress of children with autism (Magiati, Moss, Yates, Charman, & Howlin, 2011).

The Social Communication Questionnaire (SCQ)

This measure assesses the communication abilities of the child. Similar to the ATECC, the SCQ has been used in a number of autism-related studies (Charman et. al., 2007)(Norris & Lecavalier, 2010), and has been validated as an early screening measure for autism spectrum disorders, particularly for school-aged children (Chandler et. al., 2007),(Mulligan, Richardson, Anney, and Gill, 2009).

Parental Stress Scale (PSS)

The Parental Stress Scale is a measure of parental stress developed as a reliable alternative to the commonly used Parental Stress Index (Berry & Jones, 1995). This measure has been validated in Spanish (Oronoz, Alonso-Arbiol, & Balluerka, 2007) and Chinese (Leung & Tsang, 2010).

Alcohol Use Disorders Identification Test (AUDIT)

This measure is used to examine drinking behaviors in parents of children with autism. The AUDIT is a widely-used measure that is reliable, especially outside of high stakes situations (Shields &Caruso, 2003). Items 14, 15, and 17 of the AUDIT were selected to obtain information parents'

Procedure

This experiment was conducted online using the Texas A&M University Qualtrics Survey Software, an online survey website. Participants were asked to confirm that they lived with and cared for at least one child with autism, and eligible participants were then consented. The

participants were asked a series of demographic questions and then completed the Social Communication Questionnaire, the Parental Stress Scale, the Autism Treatment Evaluation Scale, the Questionnaire on Resources and Stress- Friedrich Short Form, and questions adapted from items on the Alcohol Use Disorders Identification Test were randomly presented using block randomization.

CHAPTER III

RESULTS

Only the results for participants (N=24) who completed the study fully or only declined to answer a few questions were included in the data.

Participants (N=24) were mostly mothers (male=2, female= 22), and the majority of participants described their ethnicity as white (n=17). Child ages ranged from 2-23 years old, with more male children (n=20) than female (n=4). As shown in Table 1, the majority of participants (71%) identified themselves as white, with the rest identifying as Hispanic (17%), Asian (4%), or Other (8%). The majority of reported child ethnicities were White (58%), followed by Other (29%), Hispanic (8.3%), and African American (4%), as shown in Table 2.

Table 1

Caregiver Self-Reported Demographics

	N	Cumulative Percent
Male	2	8.33
Female	22	91.67
White	17	70.8
Hispanic	4	87.5
Asian	1	91.7
Other	2	8.33
Total	24	

Table 2

Child Demographics

	Frequency	Valid Percent	Cumulative Percent
White	14	58.3	58.3
Hispanic	2	8.3	66.7
Other	7	29.2	95.8
African American	1	4.2	100.0
Total	24	100.0	100.0

Due to low participation, only the data for the two predictor variables, the ATEC and the SCQ, was analyzed against the dependent variable, the PSS. The mean score on the Social Communication Questionnaire (M=19.125, SD= 6.145) exceeded the cutoff score of 15, which indicates communication problems that may be tied to Autism Spectrum Disorder, thus supporting reports of an autism diagnosis for the child. The average total score for the Autism Treatment Evaluation Checklist (M=66.375, SD=28.423) fell within the moderate range of autism severity, but with greater deviation between participants. The Parental Stress Scale mean (M=48.958, SD=8.290) was roughly halfway between the 18-90 range of total stress points.

Correlation analyses were used to examine the relationship between the SCQ, PSS, and the ATEC as shown in Table 3. The ATEC total score was analyzed in addition to the four ATEC subscales of Speech, Sociability, Sensory, and Health/Behavior. The correlational data suggests that the SCQ scores are positively correlated with ATEC Speech (r=.696, p<.01) and Sociability (r=.421, p<.05). The SCQ is also significantly correlated with the ATEC total score (r=.687, p<.01). No significant correlations were found between the parent stress scores and the ATEC total or subscale scores. Though not significant, there was a slight correlation between parent

stress scores and higher scores on the SCQ (r=.120, p>.05) as well as the ATEC Health score (r=.367, p>.05).

Table 3

Correlations

	1	2	3	4	5	6	7
1. Social Communication Total	---						
2. Autism Speech	.696**						
3. Autism Sociability	.421*	.171					
4. Autism Sensory	.668**	.481*	.556**				
5. Autism Health	.367	.438*	.606**	.470*			
6. Autism Symptom Total	.687**	.675**	.768**	.790**	.837**		
7. Stress Total	.120	-.002	.185	.077	-.001	.084	

*Note: *= correlation is significant at the .05 level **= correlation is significant at the .01 level*

Alcohol Use

Parents reported drinking an average of 1.5 drinks (M=1.500, SD=1.128). As shown in Table 4, there were no significant correlations between parent stress and drinking behavior. The number of drinks parents had on days of alcohol consumption was negatively correlated with stress (r=-.129, p>.05). There was also a negative correlation between parent stress scores and how often this amount of alcoholic beverages was consumed (r=-.181, p>.05).

Table 4

Alcohol Consumption and Parent Stress

	1	2	3	4
1. How often do you have 4 or more drinks on a single occasion?	---	-.684**	.478*	.063
2. On days that you drink alcohol, how many drinks do you have?	-.684**	---	-.469*	-.129
3. How often do you drink this amount?	.478**	-.469*	---	-.181
4. Stress Total	.063	-.129	-.181	---

*Note: *= correlation is significant at the .05 level **= correlation is significant at the .01 level*

CHAPTER IV

DISCUSSION

The results of the current finding were not significant when investigating the relationship between social communication and autism severity with parental stress While there is a robust finding in the literature that parenting a child with autism is significantly more stressful than parenting children with other forms of disabilities (Blacher &McIntyre, 2006), it is uncertain which aspects of caring for a child with ASD are the most stressful. However, it is important to consider that the current sample size was not of sufficient power for analyses and therefore further investigation is warranted on the relationship of these characteristics. By increasing the sample size, the current study may provide further understanding of Bluth's model of parent stress with a child with ASD, as the results may elaborate upon the specific "child characteristics" dimension of this model that contribute to greater levels of parental stress (Bluth et. al., 2013).

Additionally, increased participation will allow for the examination of family resources, as measured by the QRS-F, as a moderator for caregiver stress in families with a child with ASD. Currently, there are few studies that examine the relationship between stress and certain family resources for those with a child with autism, such as income and support from the child's siblings or extended family (Bluth et. al., 2013). Bluth also addresses couple resources as a possible intervening variable, and as more data is collected, a correlation between marital status and parenting stress may emerge. This could provide more evidence for the idea that alcoholism is more common in families with a child with ASD (Miles et. al., 2003).

Significant correlation between the SCQ and the ATEC Speech, Sociability, and Total scores suggests that although the SCQ is designed to assess communication abilities of children with a variety of disorders, the ATEC measures similar aspects of child communication with the Speech and Sociability subscales. Future studies may be able to use the ATEC subscales to quickly assess communication abilities in lieu of the SCQ. However, the SCQ asks questions pertaining to both verbal and nonverbal children, and it may provide greater insight when communication ability in particular is to be examined.

Though not significant, current findings show a stronger correlation of the SCQ as a predictor of parental stress (r=.120, p=.575) compared with that of the ATEC (r=.084, p=.698). While no causal relationships between factors can be stated from this experiment, the data obtained so far shows that the hypothesis that child communication is more closely tied to parenting stress than autism severity may be confirmed with increased participation in this study.

Data from the alcohol use questions, although not significant, seems to indicate a negative relationship between the amount of drinks consumed and parent stress, as well as between alcohol use frequency and parent stress. This may mean that although parents of children with autism are under increased levels of stress, they may not be using alcohol as a coping mechanism.

Potential limitations to this study include participant self-selection, as caregivers participating in a study without compensation may be more supportive of autism-related research and

consequently more aware of parenting techniques that may reduce parenting stress. Additionally, more male participants and those reporting a caregiver role besides "parent" need to take part in the study in order to increase generalizability. Increased participation of those identifying themselves as ethnic minorities should be encouraged to lower limitations of this study, because although stress levels are constant across cultural groups, there are cultural differences in caregiver feelings of depression, moral, and positive perceptions associated with raising a child with a disability (Blacher & McIntyre, 2006). The results obtained from the Social Communication Questionnaire are also limited as the Current Form, which asks questions regarding child communication during the past three months, was used instead of the Lifetime Form.

With a larger sample size, it may be possible to use the Questionnaire on Resources and Stress-Friedrich Short Form (QRS-F) to investigate perceived parental support as a possible moderator of parent stress levels. This measure is a shorter version of the Questionnaire on Resources and Stress that is comprised of seven factors used to measure perceived stress and available support for parents of children with various disabilities (Salisbury, 1986). In addition to child characteristics, perceived available resources to deal with family crises has been shown to be predictive of stress in parents of children with developmental disabilities (Minnes, 1988). Bluth's model identifies individual resources, couple resources, and other family resources, such as family dynamics, income, and the presences of siblings to the child with ASD (Bluth et. al., 2013). Therefore, identifying parent resources as a moderator of parental stress would provide further support for the Bluth parent stress model for ASD.

Future research should be directed toward determining which factors of ASD are most strongly tied to parenting stress in order to improve interventions and to identify caregivers at a high risk for stress. While there is literature concerning parenting stress and physical and mental disabilites, there are relatively few studies that have examined stress as it relates to children with ASD, and how parenting stress in turn effects parent-child relations (Osborne & Reed, 2010). Continued research may also show support for Bluth's model, which is currently the only stress model that specifically addresses families of children with autism, and suggest future directions for family interventions, such as Bluth's suggestion of mindfulness training tailored to suit caregivers in these families (Bluth et. al., 2013).

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