Winter 2012

Stress and Coping Strategies Used by Parents When Raising a Young Child with an Autism Spectrum Disorder

Nicole M. Storms
Southern Illinois University Carbondale, storms@mchsi.com

STRESS AND COPING STRATEGIES USED BY PARENTS WHEN RAISING A YOUNG CHILD WITH AN AUTISM SPECTRUM DISORDER

by

Nicole M. Storms

B.S. in Science, Eastern Illinois University, 2006

A Research Paper
Submitted in Partial Fulfillment of the Requirements for the

Master of Science in Education

Department of Educational Psychology and Special Education
in the Graduate School
Southern Illinois University Carbondale
December 2013

RESEARCH PAPER APPROVAL

STRESS AND COPING STRATEGIES USED BY PARENTS WHEN RAISING A YOUNG CHILD WITH AN AUTISM SPECTRUM DISORDER

By

Nicole M. Storms

A Research Paper Submitted in Partial

Fulfillment of the Requirements

for the Degree of

Masters of Science in Education

in the field of Special Education

Approved by:

Deborah Bruns, Chair

Christie McIntyre

Dimitrios Anastasiou

Graduate School
Southern Illinois University Carbondale
October 22, 2013

AN ABSTRACT OF THE RESEARCH PAPER OF

Nicole M. Storms, for the Master of Early Childhood Special Education degree in Special Education, presented on October 22, 2013, at Southern Illinois University Carbondale. (Do not use abbreviations.)

TITLE: STRESS AND COPING STRATEGIES USED BY PARENTS WHEN RAISING A YOUNG CHILD WITH AN AUTISM SPECTRUM DISORDER

MAJOR PROFESSOR: Dr. Deborah Bruns

Previous research has shown raising a young child with a disability, such as an ASD, gives parents a unique set of challenges that impact their family including relationships among family members. Parents of young children with an ASD may experience many stressors. Some causes of stress when raising a child with an ASD are medical decisions, behavioral challenges, and financial impact. Parents develop individual coping strategies that are unique to their family and themselves. The purpose of this literature review is to examine the stress levels and coping strategies of parents of young children with an ASD. Results indicated parents of young children with an ASD had a higher level of stress then parents of children with other disabilities. Child's symptom severity was a key factor in stress level. One type of coping strategy many studies found was social support groups, where parents were able to vent, receive advice, and discuss their children. Social support used by parents of young children with an ASD could be formal or informal. Social supports were determined to be a main coping strategy used by parents. Parents sought counseling, support groups, and family members to address stress associated with raising a young child with an ASD.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1

INTRODUCTION

Over the past several decades, there has been an increase in the number of children diagnosed with an autism spectrum disorder (ASD). According to the Center of Disease Control and Prevention (2012), one in 88 children is labeled with an ASD in the United States. Children with an ASD must meet the criteria for ASD including lack of social skills and lack of or delays in communication (Twoy, Connolly, & Nocak, 2007).

Previous research has shown raising a young child with a disability, such as an ASD, gives parents a unique set of challenges that impact their family including relationships among family members (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). In many different studies, parents have reported positives effects of having a young child (under the age of six) with an ASD (Bayat, 2007; Marcus, Kunce, & Schopler, 2005). Mothers have reported an increase in spiritual connectedness, social support, a sense of purpose, and a community network of support (Bayat, 2007; Twoy et al., 2007). Also, parents report their child with an ASD has led to greater meaning to their lives, and enhanced empathy for others (Marcus et al., 2005). In addition to having a closer relationship with their child with an ASD, mothers of children with ASD reported better coping skills for the day to day challenges of parenting than mothers of typically developing children (Montes & Halterman, 2007).

Whille many parents report positive aspects of having a young child with an ASD, parents are also reporting higher stress levels then parents of typically developing children. Some causes of stress when raising a child with an ASD are medical decisions, behavioral challenges, and financial impact (Plant & Sanders, 2007). In addition to stress,

studies have demonstrated parents also experience anxiety, depression, and strained martial relationships (Baker-Erczen, Brookman-Franzee, & Stahmer, 2005; Lyons, Leon, Phelps, & Dunleavy, 2010; Pottie, Cohen, & Ingram, 2009).

When raising a child with ASD, it is important that the parents develop coping strategies. Turnbull and Turnbull's family systems theory can be applied here. Families have different characteristics and learn to adjust, overcome and meet challenges (Turnbull et al., 2011). Turnbull and colleagues (2011) states a family with a child with a disability needs supports and services for optimal family functioning. Further, it's important all family members receive support to meet the needs of their child with a disability (Turnbull et al., 2011, Zablotsky, Bradshaw, & Stuart, 2013). Therefore, the authors state "…enhancing the strength of the relationships among the family unit is essential in improving the health of the family unit as a whole," (p. 1381). In addition, according to Zablotsky and colleagues (2013), a weakened family unit can lead to lower levels of family coherence, family adaptability and less effective coping strategies.

Turnbull and colleagues (2011) describe the family systems framework which includes five "life management skills" (p.18) to assist parents to cope with having a child with a disability: a) reframing- changing how you are thinking, b) passive appraisal- setting aside your worries, c) spiritual support- finding comfort and guidance from spiritual beliefs, d) social support- receiving social and emotional support from friends and family, e) professional support- receiving assistance from professionals and agencies. While many studies use the term 'coping', Turnbull and colleagues (2011) defines the term to mean responding to a crisis situation whereas "life management" is a family's

responses to various daily situations (e.g., feeding issues, therapy, and social interactions with their children).

Parents who report positive aspects of having a child with ASD state they use coping strategies. One coping strategy mentioned is the use of social supports (Marcus et al., 2005; Montes & Halterman, 2007; Pottie, Ccohen, & Ingram, 2009; Schieve, Blumberg, Rice, Visser, & Boyle, 2007; Vidyasagar & Koshy, 2010). According to Twoy (2007), social supports develop from interactions between individuals such as families, peer groups such as co-workers, and other social circles (parents of their child's peers in school programs, hobbies, sports, etc).

The purpose of this paper is to review the stressors some parents may face when raising a young child with an ASD while also examining coping strategies parents have reported using in the literature. For the purpose of the literature review, a young child with an ASD is defined as being under the age of six.

CHAPTER 2

METHOD

Inclusion Criteria for Studies

Keywords used to locate articles were "*raising a child with autism", "autism, parent stress", "coping styles of parents of children with autism"," parents and autism",* and *"maternal problems in parents of children with autism"*. The keywords *"raising a young child with autism"* was also used to search for articles but no articles were located so a more general term was used "*raising children with autism."* Articles were then narrowed down to studies to samples which only included children under the age of six. The articles were first located through online searches using *ERIC*, *PsychInfo*, *EBSCO*, and *Google Scholar.* Next, the journals were reviewed looking for articles which were repeatedly cited. Articles which were repeatedly cited in other articles were searched through *ERIC, PsychInfo,* and *Google Scholar*.

Articles included in this review came from the following journals: *Pediatric; Autism; Journal of Intellectual Disability Research; Journal of the Indian Academy of Applied Psychology; International Journal of Disability, Community & Rehabilitation; Journal of Family Psychology; Journal of American Academy of Nurse Practitioners; Journal of Child Family Studies; Journal of Intellectual & Developmental Disability; Journal of Autism Developmental Disorder; Physical & Occupational Therapy in Pediatrics; Research in Autism Spectrum Disorders; Pediatrics International;* and *Journal of Pediatric Psychology.* The search generated a total of 47 articles published between 1997 and 2013. Fifteen articles reported on international studies. The international studies were not used due to variations in definitions, availability of formal

supports and overall context. Of the remaining 32 articles, ten articles compared parents of children with an ASD to parents of typically developing children or parents of children with other developmental disabilities such as Down syndrome, learning disabilities, and developmental delays.

A matrix was developed to code the articles based on several criteria (a) dependent variables, (b) independent variables, (c) dependent measures, (d) independent measures, (e) research design, (f) setting, (g) strengths of the study, and (h) weaknesses of the study. The articles were categorized based on the dependent variables, independent variables, and type and number of participants. The articles were divided into the following categories: (a) studies researching parenting stress of raising a young child with an ASD (b) articles studying coping strategies of parents raising young children with an ASD, and (c) articles comparing mothers and fathers stress levels.

CHAPTER 3

LITERATURE REVIEW

Articles that were included in this review reported levels of stress parents experienced with a young child with an ASD and corresponding coping styles and strategies. Ten articles used in this review compared stress levels of three groups of parents: (a) parents with children without an ASD, (b) parents of children with other developmental disabilities not including ASD, and (c) parents of children with an ASD. The articles were published in peer-reviewed journals between 1997 and 2013.

Characteristics of an ASD

ASD affects one in 88 children (Center of Disease Control and Prevention, 2012) and approximately four males are diagnosed with ASD for every female (Werling & Greshwind, 2013). According to Twoy and colleagues (2007), ASD is the fastest growing developmental disability with as many as 1.5 million Americans living with some form of ASD. A decade ago, ASD was typically diagnosed at four years old but current trends show children are now labeled with an ASD at approximately two years of age (Volkmar & Klin, 2005).

Kent et al. (2013) discuss the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) definition of an ASD as a child having impairments in social interactions, communication, restrictive interests, and repetitive behaviors. According to Volkmar and Klin (2005) a child must meet at least six criteria to be diagnosed with an ASD (see Table 1) with at least two characteristics in the social domain and, at least one in the communication area and interests and activities area which is defined as how a child with an ASD plays including the types of preferred play items. (Unable to access the newly published DSM-V Manual so information provided above is used to describe ASDs.)

Table 1 – Criteria for Determining an ASD

Communication (a child has to meet at least one criteria)	Restricted and Repetitive Behavior Symptoms (a child has to meet at least one criteria)	Social Interactions (a child has to meet at least two criteria)
Delay or lack of spoken communication	Preoccupied with one or more stereotyped and restricted patterns of interest	Lack of eye gaze and facial expression
Failure to initiate or sustain conversations	Compulsive adherence to specific nonfunctional routines or rituals	Failure to develop peer relationships
Patterns and repetitive language or idiosyncratic use of language	Patterns and repetitive motor mannerisms	Socio-emotional reciprocity
Lack of impromptu use of language	Preoccupied with part(s) of objects or nonfunctional components of play objects such as feel, noise, order, or texture	Lack of spontaneous speaking to share excitement/ interest/ achievements.

Note. Adapted from Kent and colleagues (2013) and Volkmar and Klin (2005)

When parents receive their child's ASD diagnosis, parents must adjust to their own feeling and the way society reacts to their child (Vidyasagar & Koshy, 2010). As described by parents in a study completed by Altiere and Kluge (2009) "Every parent [who participated in the study] viewed the discovery that his or her child has autism as a life-altering event" (p. 145).While some studies report parents do not experience an increased level of stress, others studies have shown having a child with an ASD may cause additional stress (White, McMorris, Weiss, & Lunksy, 2012). For example, parents have to adjust to new schedules and time management issues such as providing adequate time for siblings without an ASD and for each other. While some parents have reported more stress, other parents have reported because of having a young child with an ASD, they feel closer to their children and spouse because they are sharing the responsibility of

raising a child with an ASD (Johnson, 2012). Johnson (2012) stated parents of young children with an ASD have many stressors such as financial, child related behaviors, and lack of availability of therapies, often leading to marital problems.

The studies discussed below focus on stress parents with young children with an ASD experience and coping strategies used compared to other parents with a child with a disability and/or without a disability.

Determining stress among parents of young children with an ASD using rating scales

Several studies have used the *Parenting Stress Index* (Abiden, 1995) to survey parents of young children with ASD (Baker-Erczen et al., 2005; Davis & Carter, 2008; Ingersoll & Hambrick, 2011; Lecavalier, Leone, & Wiltz, 2006). Items on the *Parenting Stress Index* were rated with a Likert scale with "5" being strongly agree and "1" indicating strongly disagree. The scale determines differences between child related stress and parent- related stress using six child related subscales: (a) adaptability,(b) acceptability, (c) demandingness, (d) mood, (e) distractibility/hyperactivity, and (f) reinforce parent (Abiden, 1995). The parent subscale includes items related to the following areas: (a) depression, (b) attachment, (c) restriction of role, (d) sense of competence, (e) social isolation, (f) relationship with spouse, and (g) parent health.

Lecavalier and colleagues (2006) examined the effects a child with an ASD has on their caregivers in 243 parents in a two year longitudinal study. The children in the sample had a mean age of 9.0 years with 35% of the sample preschool or kindergarten-aged children with an ASD. For the purpose of this literature review, only the results for the preschool and kindergartens will be used. After analyzing the results of the *Parenting*

Stress Index (Abiden, 1995), it was determined behaviors were the main cause of stress in parents compared with other child characteristics such as repetitive behaviors or lack of communication (Lecavalier et al., 2006). The authors defined the behaviors which caused the parents of young children the most stress as the child being defiant, disobedient, and physically aggressive to others.

Another instrument used in several studies was the *Center for Epidemiologic Studies- Depression Scale* (Radoff, 1977) (Benson & Karlof, 2009; Davis & Carter, 2008; Ingersoll & Hambrick, 2011; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). Smith and colleagues (2008) studied mothers of toddlers with an ASD (n=15, range between 18 and 34 months) and mothers of newly diagnosed adolescents (n=201). For the purpose of this paper, the toddlers will be the only group discussed. Smith and colleagues (2008) found that mothers with toddlers with an ASD experienced high levels of depression and depression like symptoms (examples are not included). The authors further link these reported high levels of depression to stress. The authors determined that when parents reported higher levels of denial of their child's diagnosis, and behavior disengagement, (defined as reduction of efforts to address stressors), higher stress levels were also reported. In addition, higher levels of stress were reported in this study in mothers of toddlers with an ASD when compared with mothers of adolescents with an ASD.

A study by Benson and Karlof (2009) used the *Center for Epidemiologic Depression Scale* (Radoff, 1977), interviewed parents about their child's symptoms and behaviors using a five point scale (0=never to 4=hourly) and the *Effects of the Situation Questionnaire* (Yatchmenoff et al., 1998). The sample included 84 mothers and 6 fathers

of children with an ASD (mean = 6 years; participants were between the ages of three and seven). The authors found the more anger parents reported the higher levels of stress they also reported. This was measured by interviewing parents three times over several weeks. The authors hypothesized anger as a cause and stress as an effect among their sample of parents of toddlers with an ASD. The authors hypothesized that for parents of young children with an ASD, the severity of symptoms their child displayed would mediate the effect of stress on parent depression. For example, when the young child would display sever symptoms of an ASD, the parents would become more depressed. The study also found the more severe ASD symptoms their toddlers s demonstrated, the more anger the parents reported. This appeared to result in higher levels of stress as reported by parents (Benson & Karlof, 2009). The authors state "our analysis suggests that anger serves both as an important cause and an important effect of stress proliferation among parents of children with ASD" (p. 359).

Benson and Karlof (2009) and Smith and colleagues (2008) used the *Center for Epidemiologic Depression Scale,* and found different results. Smith and colleagues (2008) found that severe ASD symptoms in areas such as social reciprocity, communication, and repetitive behaviors were not predictors of stress. Benson and Karlof (2009) found the opposite. The more severe the child with an ASD symptoms were, the more stress parents reported.

Estes and colleagues (2009) and Lyson, Leon, Roecker Phelps, and Dunleavy (2010) used the *Questionnaire on Resources and Stress-Friedrich Short Form* (QRS-F; Friedrich et al., 1983) to examine stress in parents of young children with an ASD. The QRS-F is a 52 item true–false questionnaire which measures four factors: (a) parents and

family problems, (b) pessimism, (c) child characteristics, and (d) physical incapacity (Friedrich et al., 1983). Estes et al. (2009) used the QRS-F to compare parents of young children with an ASD (n=51, mean=43.88 months) and parents of children with developmental delays (n=22, mean =43.32 months). Mothers of young children with an ASD reported higher levels of parenting stress compared with mothers of children with developmental delays. Neither the children's diagnosis of an ASD, nor the child's lack of daily living skills related to the mothers' parenting stress but rather the problematic behaviors the child demonstrated (Estes et al., 2009). Problematic behaviors in the study were defined as irritability, social withdrawal, stereotypic behavior, hyperactivity, non-compliance, and inappropriate speech. Similar to other studies which found when parents with young children with an ASD reporting more stress (Benson & Karlof, 2009; Smith et al., 2008). Estes et al. (2009) found that parents of children with an ASD with problem behaviors such as aggression and repetitive behaviors also reported higher stress levels.

Similar to Montes and Halterman (2007), Baker- Erczen and colleagues (2005) found when parents of young children with an ASD participated in support groups, parents experienced less stress. Baker-Erczen and colleagues (2005) studied parents (mothers and fathers) of typically developing toddlers (n=23, mean=24.35 months) and toddlers with an ASD (n=37, mean=28.35 months) to determine if parents experienced more stress when their child with an ASD was enrolled in an inclusive preschool setting by responses to the *Parenting Stress Index* (Abiden, 1995) described above. Parents completed the PSI as their children entered the inclusive preschool program and upon exiting the program. Results showed that mothers and fathers of children with an ASD experienced high levels of stress regardless of their child's placement (inclusive

preschool was the only placement option described in the study) (Baker-Erczen et al., 2005). The one item which showed a decrease in the amount of stress parents experienced was related to child stress. Parents reported less stressed at the end of the preschool year compared with the beginning of the year when the stress was associated with child-related stress. Child-related stress in this study was defined based on child characteristics such as behavior, and repetitive actions.

Baker- Ecrzen and colleagues (2005) also found parents of young children with an ASD had a deceased amount of child related stress over time. In other words, parents were becoming less stressed because of their children's repetitive behaviors, aggressive behaviors, and lack of communication. The authors did not state why their sample of parents of young children with an ASD reported less stress. Whereas the study by Lecavalier and colleagues (2006) used the same rating scale, results found parents of children with an ASD reported an increased amount of stress due to the aggressive and disobedient behaviors of their child.

Using social support as a coping strategy

In the last decade, researchers have found that parents of young children with an ASD face higher levels of stress then parents of typically developing children or with other types of developmental disabilities. Studies also report parent use of coping strategies to help overcome stress associated with raising a young child with an ASD (Baker-Erczen et al., 2005; Montes & Halterman, 2007; Schieve et al., 2007). Often, one type of coping strategy parents use when raising a young child with an ASD is formal social support (Altiere & Kluge, 2009). Formal social support can be provided by doctors, psychologists, social workers, counseling and/or teachers. According to Altiere

and Kluge (2009), many times after receiving formal social support, parents begin to receive informal social support from friends, family members, and support groups.

Montes and Halterman (2007) and Schieve and colleagues (2007) reviewed data from the National Survery of Children's Health. The studies included 459 children between the ages of four to seventeen years with an ASD, and 61,408 families of children without an ASD. The review by Schieve and colleagues (2007) focused on children under the age of six with an ASD. Data indicated parents of younger children with an ASD could not be distiguished from parents with older children with or without an ASD including children who were typically developing or diagnosed with Down syndrome with respect to having a close relationship to their child and coping with parenting tasks (Schieve et al., 2007).

According to Montes and Halterman (2007), mothers of young children with an ASD also reported coping, defined as having someone to turn to for emotional suport such as a family member or close friend, as a way to reduce stress. Montes and Halterman (2007) found that mothers would not only seek a support group to help them cope and to provide support. Mothers also reported having someone they could turn to for day to day emotional help with parenting their young child with an ASD.

Many studies describe the use of social supports by parents of children with an ASD. Schieve and colleagues (2007) compiled data which found that mothers of children with ASD were more likely to seek support groups or others for support in learning about their child's disability and stress related to their child's disability. According to Pottie et al. (2009), there are two types of social support used by parents of children with ASD. One type of support is received support which refers to receiving assistance from others

which has been found to been most useful the day the support is received. The other type of support is perceived support, which refers to "one's perceptions of the availability of support and satisfaction with the support which is provided" (p. 419). Pottie and colleagues (2009) also hypothesized that received support can yield more practical implications for interventions then perceived support. Received support can be better for a parent of a young child with an ASD because the parent is receiving tangible support whereas, in perceived support, a parent may think they are receiving support when no support is actually provided.

To further examine their hypothesis, Pottie, and colleagues (2009) compared mothers (n=64) and fathers' (n=36) ratings of daily stress in raising a young child with an ASD (n=93, mean=88 months). The authors used a method proposed by Stone and Neale (1984) to assess daily stress by using a modified version of the *Daily Coping Inventory* and the *Positive and Negative Affect Schedule* (Watson, Clark, & Tellgen, 1988). The *Daily Coping Inventory* asks parents to describe a problem and then rate the stress of the problem on a seven- point scale (0=not at all, 6=extremely). The *Positive and Negative Affect Schedule* asked parents to rate 20 emotional adjectives such as attentive, strong, nervous, etc to describing their mood that day on a five point scale (1=very slightly or not at all, 5=extremely) (Watson, et al., 1988). Pottie, Cohen, and Ingram (2009) found, overall, mothers reported higher daily stress compared with fathers. It was found that higher daily stress was predicted when their young child with an ASD demonstrated disruptive and oppositional behaviors on the day data was gathered.

Differential stress in mothers and fathers of children with an ASD

Most studies only include mothers of young children with an ASD. It is also important to determine if fathers have an increased level of stress when raising a child with an ASD. Several studies included both parents (Altiere & Kluge, 2009; Baker et al., 2003; Davis & Carter, 2008; Lyons et al., 2010; Plant & Sanders, 2006; Pottie et al., 2008) and compare the stress of mothers to fathers of young children with an ASD. In studies discussed in the previous sections, fathers have been included but there was not a direct comparison of mother's stress and coping strategies to father's stress and coping related to their young child with an ASD.

Plant and Sanders (2007) used a series of checklists modified for their study (the checklist names were not provided). The authors studied 105 families of children with a developmental disability. Twenty-three percent of the sample had a child with an ASD. The children in the study were under the age of six and in preschool (mean=49.71 months). The first checklist used in the study asked parents about their typical day and to identify common tasks such as daily tasks the parents may do (preparing meals, bathing their children). With the results of the first checklist, a second checklist was developed with only the common daily tasks mothers and fathers listed (Plant & Sanders, 2007). The tasks included direct care task such as bathing, feeding, providing in home therapy, out of home therapy or appointments, supervision, involvement in leisure activities, educational activities, advocating for their child, and managing behaviors. (The authors do not specify what types of behaviors.) Parents were asked to rate the tasks using a seven point scale (1=not stressful to 7=extremely stressful).

Overall, the study found both mothers and fathers reporting daily care tasks as stressful including helping and supervising meals, settling a child for bedtime, and

supervising toileting (Plant & Sanders, 2007). The authors found mothers reported feeling less stress then fathers when cleaning up after their child, while fathers found advocating for their child less stressful than mothers. Fathers also reported feeling little stress when playing with their child at home and outside of the home, taking their child to an appointment, and preparing resources and activities for their child. The authors found mothers reported feeling less stress in relation to playing with their child in and outside of the home, preparing resources and activities, filling out forms about their child, helping with teeth cleanings, and providing some types of medical care.

While Plant and Sanders (2007) found mothers and fathers may both experience higher levels of stress when raising a young child with an ASD, Davis and Carter (2008) found fewer parents with clinical levels of stress then originally hypothesized. Davis and Carter (2008) completed a study on 54 sets of parents of toddlers with an ASD. Parents completed the *Beck Anxiety Inventory* (Beck et al., 1998), *Center for Epidemiologic Studies Depression Inventory* (Radloff, 1977), and *Parenting Stress Index* (Abiden, 1995). Results of the assessments found 50% of mothers experience clinical level of stress in relation to their parent –child relationship, whereas results indicated 39% of fathers had clinical levels of stress (Davis & Carter, 2008). This is shows a significant different between mothers and fathers and their stress levels. While the sample size in the study is small, the authors feel in a larger study differences in stress levels between mothers and fathers raising young children with an ASD stress levels may be larger.

A study by Davis and Carter (2008) found that parents of young children with an ASD experience added stress when their children had been recently diagnosed. However, they did not always experience clinical levels of stress high enough to be diagnosed by a

medical professional. Conversely, Plant and Sanders (2007) state “taken together, these findings highlight the need to assess parental stress and depressive symptoms while at the same time recognizing that many families bring important strengths in coping and adjusting to the diagnosis of ASD” (p.1288).

Overall, parents are reporting high levels of stress when compared to parents of children without an ASD (Monte & Halterman, 2007; Este et al., 2009). Parents are using social support as a coping strategy to help overcome some of the added stress. Social support can be both formal and informal support. Formal social support comes from therapist and professionals who work with families of children with an ASD, and informal social support is support from friends, family and support groups.

CHAPTER 4

DISCUSSION

Through various rating scales and other assessments, it was determined most parents of young children with an ASD experience clinical levels of stress. The main cause of the stress according to studies is behaviors children with an ASD may have such as aggressive behaviors toward themselves and others (Lecavalier et al., 2006; Plant & Sanders, 2007; Pottie, et al., 2009). Another cause of added stress among mothers and fathers according to Plant and Sanders (2007) is completing daily care task such as preparing meals, cleaning up after their child, and bath time.

Studies have assessed parents of young children with an ASD and compared their results to parents of children with Down syndrome and parents of children who typically developing (Estes et al., 2009; Montes & Halterman, 2007, Schieve et al., 2007). The studies have found parents of young children with an ASD experience more stress than other groups of parents such as parents of Down syndrome, parents of children with a developmental delay, and parents of children who are typically developing. Some of the reasons why parents of children with an ASD experience higher levels of stress are because children with an ASD may demonstrate repetitive behaviors and aggression. Parents also reported experiencing added stress because of lack of communication and social skills.

One coping strategy repeated mentioned in the studies was the use of social supports. Social supports have been defined in many different ways. One study defined social supports as learning from others and participating in a support group to learn more about their young children with an ASD (Schieve et al., 2007). Pottie and colleagues

(2009) defined social support as a way for parents to receive some type of support from anyone around them. While each study defines social support slightly differently, it is important to know there is agreement on a general definition. Studies focusing on social support as a coping strategy discuss the need for support from others whether a support group, friends, family, co-workers, other parents, or professionals.

Limitations

There are a number of limitations across the reviewed studies. Many studies have a small sample size. For example, Pisula and Kossakowska's sample (2010) consisted of 26 families. When the sample size is small, results cannot be generalized. While there are fewer girls diagnosed with an ASD (Werling & Greshwind, 2013), the studies reviewed here confirm this. For example, a study completed by Tobing and Glenwick (2002) had six female children in 54 families who participated in the research.

There are studies examining the affects having a young child with an ASD has on their parents' stress levels and coping strategies (Bayat, 2007; Davis & Carter, 2008; Schieve et al., 2007; Smith et al., 2008), but few studies only investigate families with a young child with an ASD. Learning more about this subgroup can assist teachers and other professionals who work with younger children with an ASD and their families. In addition, studies used a variety of rating scales making it difficult to compare results across studies.

An additional limitation is the lack of longitudinal studies. In the current literature review, there was one study which looked at parents of young children with an ASD over two years. Parents changed over the years and the amount of stress they experience can change for the positive or negative depending on the demand of their child with an ASD.

Children can go from exhibiting few or no behavior problems to aggressive behaviors in a short amount of time. It is critical parents' stress level and coping styles are analyzed over time (e.g., three years).

Future research

Future research is needed in determining the long term effects of various coping strategies on stress. A longitudinal study needs to be completed to determine if the coping methods are effective in eliminating stress parents face when raising a young child with an ASD. Another topic for further research is additional comparisons of mothers and fathers of young children with an ASD. This is necessary because it appears that mothers and fathers react differently to stress (Davis & Carter, 2008; Plant & Sanders, 2007) and corresponding coping strategies may be different.

In the studies reviewed, only two studies had large sample sizes (Monte & Halterman, 2007; Schieve et al., 2007). Research needs to be completed with larger sample sizes. The lack of large samples does not provide adequate representation of the population of parents of a young child with an ASD. In addition, small sample size studies can then confirm data gathered in large studies and provide researchers with specific details about how families adjust to having a young child with an ASD in the family. Additional studies need to be completed with larger sample sizes in different areas of the United States with an emphasis on recruiting diverse families. In addition, in-depth case studies and multiple interviews should be considered as additional means to investigate stress and coping strategies. Studies should also include parents of children with an ASD at different ages to determine how parent stress levels change as their children gets older.

Implications

The research reviewed here has shown that parents of young children with an ASD often face greater levels of stress, anxiety, depression, and psychological distress than other parents. Results appear to indicate that parents of young children with an ASD may experience more stress due to the unique characteristics of their children's disability. It is important to remember, while parents may report a higher level of stress when raising a young child with an ASD, not all parents experience this added stress. It is also important to learn more about parents with lower stress levels. An additional potential stressor is the financial impact of having a young child with an ASD. The reviewed research does not provide any coping strategy to help parents overcome the added burden of financial hardships in raising a young child with an ASD. This is an area in need of further study.

Children with an ASD have many unique characteristics. Each set of parents raising young children with an ASD experience different behaviors. Their children also demonstrate a range of symptoms. Parents have to be willing to try different types of coping strategies to adjust to these behaviors and symptoms related to ASD.

While each child with an ASD has unique charateristics, each family is also made of different characteriscs such as racial background. According to Travers, Tincani, and Krezmein (2013), there are a few differences across racial groups diagnosed with an ASD. Children from Asian/Pacific Islander descent were diagnosed at approximately twice the rate compared with Caucasian and African American children in 2000. By 2006, Causcasian children were diagnosied with an ASD more than any other racial group while children who identified themselves as Native American and Hispanic were

labeled at apprxomately half the rate as Caucasian children (Travers et al., 2013). Interestingly, households with young children with an ASD are more likely to have two parents although one parent may not be the child's biological parent (mother and father or mother and step-father) (Schieve et al., 2007). In the studies reviewed here, there is an overall lack of diversity in the samples (Bayat, 2007; Benson & Karlof, 2009; Montes & Halterman, 2007; Smith et al., 2008).

According to Turnbull and colleagues (2011), professionals need to support parents of children with an ASD such as strengthening the marriage subsystem. Parents report lower marriage satisfaction when they have a child with an ASD (Brobst, Clopton, & Hendrick, 2009). Turnbull et al. (2011) states that professionals need to build partnerships with parents. This can be especially critical for parents raising a child with an ASD**.** A partnership can give parents another adult to talk to about their child, sibling relationships marriage and the like.

Professionals who are close to families with young children with an ASD or work with the families need to be able to provide different coping strategies for parents of young children with ASD. The activities will provide parents with activities to participate in with their children. Also, providing school and community wide activities geared to children with an ASD can help parents meet other parents with children with an ASD and build formal and informal social supports.

Parents do not always tell professionals what they are feeling, problems they are having at home or overall stress level. Professionals have to know when to provide extra attention to the parents. A professional may be the first person a parent approaches when they are experiencing added stress related to their child with an ASD. While teachers and

other professionals seek out professional development on assessment tools and teaching strategies, they may not look for research on parental stress and coping strategies. It is imperative professionals educate themselves in these areas and share this information with other professionals who may work with parents of young children with an ASD.

Most schools offer counseling to children with disabilities. It is key to offer counseling and related resources to parents as well. Social workers can also provide counseling to parents and help them determine which type of coping strategy works for them. Teachers and therapists offer a listening ear to parents and help parents talk through their problems and offer solutions. Parents experience so many different things when their child is diagnosis with an ASD that they need to have someone that they can talk to whether it is at a hospital, school, or community agency or program.

Special education teachers focus on meeting their students' academic, behavioral and social needs but it is also equally important to work with and build relationships with parents (Dunst, 2002). Many teachers only focus on their students' needs when the focus should include family unit and assistance to address the needs of all family members. For example, teachers can encourage parents, actively listen to parents, and offer resources to address stress. Teachers should also suggest ways to elevate stress and introduce coping strategies that may be useful to parents.

According to Baker- Erczen and colleagues (2005), one reason parents of children with an ASD may report more stress is because children in preschool are not being taught social skills. This perceived lack of social skills training was viewed by parents as necessitating more emphasis in classroom instruction (Baker-Erczen et al., 2005) when in

fact on the core foundations in preschools are to help children develop social skills in the areas of play, communication, and etiquette.

Conclusion

Research has shown parents of young children with an ASD face many challenges such as aggressive behaviors, lack of communication, and poor social skills, which can lead to increased stress. This literature review suggests that parents who experiencing higher levels of stress have reported using social supports as a coping strategy. It is important to further explore this area in order to determine additional coping strategies that could assist parents in overcoming stress when raising a child with an ASD.

REFERENCES

Abidin, R.R. (1995). *Manual for Parenting Sstress Index manual*. Odessa, Fl; Psychological Assesment Resources.

Altiere, M. J., & von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual & Developmental Disability*, *34*(2), 142-152. doi:10.1080/13668250902845202

Baker, B., McIntyre, L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental deay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*, 217-230.

Baker-Erczen, M., Brookman-Franzee, L., & Stahmer, A. (2005). Stress levels and adaptaability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilites, 30*(4), 194-204.

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellecctual Disability Research, 51*(9), 702-714.

Benson, P.R., & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders, 39*, 350-362. Doi: 10.1007/s10803-008-0632-0

Davis, N.O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Austim and Developmental Disorders,38,* 1278-1291. doi: 10.1007/s10803-007-0512-z

Dunst, C. J. (2002). Family-centered practices: Birth through high school. *Journal of Special Education, 36*(3), 139-147.

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.-H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delays. *Autism, 13*(4), 375-387. doi: 10.1177/1362361209105658

Ingersoll, B., & Hambrick, D. Z. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 5*(1), 337-344. doi:10.1016/j.rasd.2010.04.017

Johnson, J. (2012). Treating couples raising children on the autism spectrum: A marriage-friendly approach. *Contemporary Family Therapy, 34,* 555- 565. doi: 10.1007/s10591-012-9213-7

Kent, R. G., Carrignton, S. J., Couteur, A. L., Gould, J., Wing, L. Maljaars.J., … Leekam, S. R. (2013). Diagnosing autism spectrum disorder: Who will get a DSM-5 diagnosis? *Journal of Child Psychology and Psychiatry*, doi: 10.1111/jcpp.12085

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*(3), 172-183. doi: 10.1111/j/1365-2788.2005.00732.x

Lyons, A. M., Leon, S. C., Roecker Phelps, C. E., & Dunleavy A. M. (2010). The impact of child symptom severity on stress among parents of children with ASD: The

moderating role of coping styles. *Journal of Child and Family Studies, 19*, 516-524, doi: 10.1007/s10826-009-9323-5

Marcus, L.M., Kunce, L.J., & Schopler, E. (2005). *Working with Families.* In F.R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.) (3rd edition), *Handbook of autism and pervasive developmental disorders* (p. 1055-1086). Hoboken, NJ: John Wiley & Sons, Inc.

Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A popilation-based study. *Pediatrics, 119*, 1040-1046. doi: 10.1542/peds.2006-2819

Plant, K.M., & Sanders, M.R. (2007). Predictors of care-givers stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research, 51*(2), 109-124.

Pottie, C. G., Cohen, J., & Ingram, K. (2009). Pareting a child with autism: Contextual factors associated with enhanced daily parental mood. *Journal of Pediatric Psychology, 34*(4), 419-429. doi: 10.1093/jpepsy/jsno94

Radoff, L.S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 385-401. doi:10/1177/014662167700100306.

Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics, 119*(Suppl. 1), S114-S121. doi: 10.1542/peds/2006-2089Q

Smith, L. E., Seltzer, M. M., Tager-Flusberg, H., Greenberg, J. S., & Carter, A.S. (2007). A comparative analysis of well-being and coping among mothers of toddlers and

mothers of adolescents with ASD. *Journal of Autism and Developmental Disorders, 38,* 876-889. Doi: 10.2007/s/10803-007-0461-6

Stone, A. A, & Neale, J. M. (1984). New measure of daily coping: Development and preliminary results. *Journal of Personality and Social Psychology, 46,* 892-906.

Travers, J. C., Tincani, M., & Krezmien, M. P. (2013). A multiyear national profile of racial disparity in autism identification. *Journal of Special Education*, *47*(1), 41-49. doi:10.1177/0022466911416247

Tunali, B. & Power, T. G. (2002) Coping by redefinition: Cognitive appraisals in mothers of children with autism and children without autism. *Journal of Autism and Developmental Disorders, 32*(1), 25-34.

Turnbull, A. P., Summers, J. A., Turnbull, R., Brotherson, M. J. Winton, P., Roberts, R., &Stroup-Rentier, V. (2007). Family supports and services in early intervention: A bold vision. *Journal of Early Intervention, 29*(3), 187-206.

Turnbull, A., Turnbull, R., Erwin, E. J., Soodak, L. C., & Shogren, K. A. (2011). *Families, profressionals, and exceptionality: Positive outcomes through partnerships and trust* (6th ed.). Upper Saddle River, NJ: Pearson/Merrill/Prentice Hall.

Twoy, R., Connolly, P. M., & Novak, J. M. (2007). Coping strageies used by parents of children with autism. *Journal of American Academy of Nurse Practitioners, 19*, 251-260. doi: 10.1111/j.1745.7599.2007.00222.x

Vernon, T. W., Koegel, R. L., Dauterman, H., & Stolen, K. (2012). An early social engagement intervention for young children with autism and their parents. *Journal of Autism Developmental Disorders. doi: 10.1007/s10803-012-1535-7*

Vidyasagar, N., & Koshy, S. (2010). Stress and coping in mothers of autistic children. *Journal of the Indian Academy of Applied Psychology, 36*(2), 245-248.

Volkmar, F. R. & Klin, A. (2005). *Issues in the classification of autism and related conditions.* In F.R. Volkmar, R. Paul, A. Klin, D. Cohen (Eds.) (3rd edition), *Handbook of autism and pervasive developmental disorders* (p. 5-41). Hoboken, NJ: John Wiley & Sons, Inc.

Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect The PANAS scales. *Journal of Personality and Social Psychology, 54,* 1063-1070.

Werling, D. M. & Greshwind, D. H. (2013). Sex differences in autism spectrum disorder. *Current Opinion in Neurology, 24*(2), 146-153. doi:10.1097/WCO.0b013e32835ee548

White, S. E., McMorris, C., Weiss J. A. & Lunsky, Y. (2012) The experience of crisis in families of individuals with autism spectrum disorder across the lifespan. *Journal of Child and Family Studies, 21*, 45-465. doi: 10.1007/s10826-011-9499-3

Yatchmenoff, D. K., Koreen, P. E., Friesen, B. J., Gordon, L. J., & Kinney, R. F. (1998). Enrichment and stress in families caring for a child with a serious emotional disorder. *Journal of Child and Family Studies, 7*, 129-145. doi: 10.1023/A:1022935014502

Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum

disorders. *Journal of Autism and Developmental Disorders, 43,* 1380-1393. doi: 10.1007/s10803-012-1693-7

VITA

Graduate School
Southern Illinois University

Nicole Storms

storms@mchsi.com

Eastern Illinois University
Bachelor of Science with minor in History, December 2006

Research Paper Title:
STRESS AND COPING STRATEGIES USED BY PARENTS WHEN RAISING A YOUNG CHILD WITH AN AUTISM SPECTRUM DISORDER

Major Professor: Deborah Bruns