Coping strategies and stress levels of parents of children with autism

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COPING STRATEGIES AND STRESS LEVELS OF
PARENTS OF CHILDREN WITH AUTISM

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of the requirements for the

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ABSTRACT

Coping Strategies and Stress Levels of Parents of Children with Autism

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The purpose of this study is to assess stress levels and coping strategies of parents with children with autism. The goal is to identify the resources and support systems which parents use for coping with their stress and to assess whether the support systems differ between mothers and fathers. This study will also investigate differences in coping strategies used by parents of children with autism and parents of typically developing children.

Subjects in this study included thirty parents of children with autism, and thirty parents of typically developing children. All participants were recruited from the Eastern, Midwest, and Western part of the United States. All participants' children ranged from two through eleven. Participants filled out a demographics questionnaire, the Parenting Stress Index, and the Coping Inventory for Stressful Situations. The participants with children with autism also participated in a follow up interview.

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Results revealed that parents who had a child with autism reported higher child related stress than parents without a child with autism. Parents with children with autism also reported more life stress than parents without children with autism. Parents with typically developing children used more task oriented coping than parents of children with autism. Males also used significantly more task oriented coping than females. Results indicated that parents of children with autism engaged in more emotion oriented coping and that females engaged in more emotion oriented coping than males. Females also engaged in more avoidance oriented coping and distraction coping than males. Results revealed that females used social diversion coping more than males.

Parents rated their spouse as their most frequently used resources in coping with their child.

There are many implications from this study including teaching parents behavioral strategies, addressing financial concerns, and encouraging families to join a support group. Parents should be encouraged to continue the use of their spouse and family for support in helping managing their stress.
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I would like to thank Dr. Bob McDermid for his willingness to give me a refresher course on SPSS and for helping me with the statistical analysis. I would also like to thank Dr. Bill Healey for his intellectual challenges throughout my graduate degrees.

I could not have completed this study without the gentle prodding of my husband, John Freitas, who helped me through every step of this project with his love and invaluable guidance. I would like to thank my father, Jerry Neil, for his love and continual encouragement throughout my educational career. Most of all, I would like to thank the Lord Jesus Christ for his faithfulness and for giving me the strength to successfully finish yet another journey in my life.
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CHAPTER ONE

INTRODUCTION

Stressors are defined as life events that have a negative impact on a person and can create change in a family unit. Examples may range from moving from one house to another, to the diagnosis of a child with a disability (Byrne & Cunningham, 1985). Although there are many definitions of stress, it is generally used to describe the response an individual elicits to a stressor. Stress can be manifested in many ways including psychologically, physically or both. Although many individuals have stress in their lives, few can identify with a parent who receives the news his/her child has autism. LeMasters (1965) researched stress in parenthood and noted that parenthood itself can represent a crisis, but even more stress is added when a child has a disability. Bristol and Shopler (1984) documented that parents of children with autism report greater stress and depression than parents of children who are typically developing. Some parents have described the feeling of finding out their child has autism as “empty,” “astonished,” “disbelief,” and “stunned” (Harris & Weiss, 1998; Simpson & Zionts, 1992). Although there has been much research in recent years on the stress and the abilities to cope with a child with autism, parents continue to face struggles and challenges in raising their child.

Coping is a part of life that everyone has to engage in everyday. Robson (1999) stated that stress is something that everyone experiences in their lives and can not be avoided. When a stressful situation occurs, an individual must cope with it. There are a variety of ways in which this may occur. Coping requires
thought about the decisions that need to be made in every aspect of daily living. Thoughts and decisions can be influenced by moods, emotions, and reactions that each individual incurs. These thoughts and decisions can be either negative or positive in nature. These thoughts also play a significant role in the ability to cope and adapt to specific situations. Holahan and Moos (1985) found the more successful coping strategies used, the more adaptable one becomes and the higher the tolerance built up to stressful situations. There has been little research done on the differences in coping strategies used between mothers and fathers. If mothers and fathers use different coping strategies to manage their stress, it would be noteworthy to find which strategies are more successful.

It has been reported that parents who have children with autism have higher stress levels than those parents without children with autism (Dewey, 1999; Kasari & Sigman, 1997; Sanders & Morgan, 1997), however, there is no research that suggests whether that stress is parent-oriented or child-oriented. That is, parents may feel more stress related to financial responsibilities, lack of support from their spouse, or how restricted their life is as a parent, which are all examples of parent-oriented stress. Child-oriented stress is parents' feelings about their child's behaviors, how demanding the child is, or the adaptability or mood of their child. This is important for all parents to know regardless of whether their children have disabilities or not. For example, if we know that parents of children with autism have more child-oriented stress than parents without children with autism, we may conclude that the parent who has the child with autism may need resources for helping with the child's behaviors associated with the disorder, behavior modification for example. If we know that parents of children without autism have more child-oriented stress, we may conclude that it could be helpful to look at their parenting skills. In other words, parents may need different resources or support based on which kind of stress they
experience most, and whether they have a typically developing child or a child with autism.

Autism is a pervasive developmental disorder affecting approximately 1 in 1000 children in America. It is 4:1 more common in males than females although the reason for this is unknown. Autism is found among all ethnic populations and distributed evenly throughout all socioeconomic classes (Gillberg, 1990). Individuals who are diagnosed with autism must exhibit the characteristics before the age of three. There are several characteristics one may present to be diagnosed with autism as it is a spectrum disorder, so each individual may present different characteristics within the criteria (Maurice, Green, & Luce, 1996). There are numerous perspectives from professionals who are knowledgeable about autism, however, most will agree that it is characterized by severe impairment and delays in social, emotional, and intellectual functioning, especially language.

Purpose

The purpose of this study is to assess the stress levels and coping strategies of parents with and without children with autism. The goal is to identify the resources and support systems which parents use for coping with their stress and to assess whether the resources and support systems differ between mothers and fathers. The study will investigate whether there are differences in coping strategies utilized by parents of children with autism and parents of typically developing children. It is my hope that through the information gained from this study, mental health professionals and educators will help parents develop better coping skills when managing the stress associated with parenting their child.
Research Questions

1. Do mothers and fathers of children with autism use different coping strategies to manage the stress associated with parenting their child?

2. Do parents who have children with autism report different stress levels on the parent and child domain of the PSI than parents without children with autism?

3. Do parents of children with autism differ in reported coping strategies as compared to parents without children with autism?

4. Will there be a statistically significant interaction between gender and parent group on each of the dependent variables?

5. What are the resources rated as most frequently used by parents of children with autism?

Hypotheses

It is hypothesized that (1) There will be a statistically significant interaction between gender and parent group on each of the dependent variables. (2) Parents who have children with autism will report different stress levels on the parent and child domain of the PSI than parents without children with autism. (3) Mothers and fathers will use different coping strategies to manage their stress. (4) Parents of children with autism will report different coping strategies than parents without children with autism. (5) The most frequent resources used by parents of children with autism will be: support from spouse, support by friends, support group, and the agency where their child is receiving treatment.

Limitation of the Study

A limitation to the current study is the problematic issue of categorizing disabilities. Some disabilities are difficult and even impossible to diagnose at an
early age and children are frequently diagnosed as having developmental delay until another appropriate diagnosis is made. For these reasons, it is possible that there may be children in this study who are misdiagnosed with autism. Another limitation of this study is the guidelines and categories that different states use for diagnosing children. Also limiting this study is the minimal population of children who have autism and the availability to attain participants for the study.

Benefits

A possible benefit to the field of autism is to understand the stress parents can experience when their child is diagnosed with autism. With adequate resources, the current research findings may prepare parents for making essential changes regarding their child with a disability. With these modifications, parents may expect less stress in meeting the challenges of parenting their child. Another benefit which may result is the cognizance of parents to examine their current coping strategies and potentially make alterations so they may be successful in managing their stressful situation.

Definition of Terms

Children with autism

In 1943, Kanner coined the term autism for eleven children whose behaviors he observed to be “different” than those of other children. He developed ten categories for the behaviors he observed: 1) inability to develop relationship with others, 2) delay or lack of speech or acquisition of speech, 3) non-communicative use of speech, 4) echolalia and delayed echolalia, 5) pronomial reversal, 6) repetitive behavior and stereotypical play, 7) need for routine or sameness, 8) lack of or no imagination, 9) exceptionally good rote memory skills,
and 10) normal physical appearance (Kanner, 1943). Through many studies and research, these ten categories were consolidated into four categories: 1) abnormal social relationships, 2) impaired language, echolalia, impaired receptive skills, and pronomial reversal, 3) need for routines and sameness, and 4) abnormal cognitive development (Berkow, 1987).

Another similar definition to Berkow’s is the criteria in the Diagnostic and Statistical Manual, 4th edition (DSM-IV) (American Psychological Association, 1994). The only difference between Berkow’s and the DSM-IV definition is the pronomial reversal which is found in Berkow’s categories of autism, but not in the DSM-IV definition of autism. According to the DSM-IV, Autism Disorder is defined as follows:

299.0 Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3);

1) Qualitative impairment in social interaction as manifested by the following:
   (a) Lack of social interaction such as nonverbal behavior, and lack of eye contact
   (b) No social play
   (c) Lack of social and/or emotional retribution
   (d) Inappropriate or no peer relationships

2) Qualitative impairment in communication as manifested by the following:
   (a) No or lack of communication such as language, facial expression, gestures and eye contact
   (b) Inability to have a conversation with others including turn-taking and maintaining a topic

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(c) Lack of imitative play such as pretending
(d) Marked abnormalities in the production of speech such as pitch, volume and rate
(e) Abnormalities in speech including repetitive or echolalia speech

(3) Limited skills of activities and interests, and stereotyped behaviors as manifested by the following:
(a) Repetitive and nonfunctional behavior such as spinning, hand-flapping, or whole body movements
(b) Preoccupation with one interest and essentially no interest in other things
(c) Preoccupation with parts of objects such as an attachment to a particular object, or repetitive smelling of an object
(d) A strong adherence for sameness and routine

B. Onset must be during the childhood years (pp. 66-67).

In addition to the primary characteristics of autism, there are other features that are often associated with the condition. These other characteristics are not necessary for the diagnosis of autism, however, they are often observed in these children: abnormalities in drinking or eating, abnormalities in sleeping, severe mood change, seizures, mental retardation, tics, and unusual food cravings. Although these symptoms do not have to be present, they are often secondary characteristics in children with autism.

Children with disabilities

In the referenced literature, children with disabilities other than autism may include: mental retardation, Down syndrome, learning disabilities, behavioral and emotional disabilities, and physical disabilities such as cerebral palsy, blindness, and deafness.
**Children without disabilities and typically developing peers**

Typically developing peers include those children who do not have any identified disabilities and are developing within the average range compared to their typical-aged peers.

**Parents**

For the purpose of this study, the term “parent” is used to describe the individual who has primary responsibility for the rearing of the child. This may include a biological parent, a step-parent, a grandparent or a guardian.

**General stress**

For the purpose of this paper, the following definition of stress will be utilized. Miller and Smerglia (1998) defined stress as an individual’s response to a traumatic life event such as feeling uneasy or upset. This can also include other life events, problems, or changes that accumulate. For obvious reasons, an individual’s experience of stress can vary to a great extent depending on the person and the coping strategy they use to manage that stress.

**Life stress**

The following definition will be used for life stress adopted from the Parenting Stress Index (Abidin, 1983). Life stress includes any of the following events occurring in one’s life during the past twelve months: divorce, marriage, separation, pregnancy, income decrease or increase, relocation, alcohol or drug problem, death of family or friend, legal problems, problems at school or work, and beginning a new job.
Coping strategies

Coping strategies were defined as the changing of an individual's thought process and behavior to manage stressful life events in which a person does not have adequate resources to otherwise manage them. Although some authors use the term “coping abilities,” for the purpose of this paper, coping strategies will be used.

Internal resources

Internal resources are those resources available to parents through their family and friends including immediate family and extended family. These resources may consist of emotional support, assistance in finding other resources, babysitting or respite care, and financial aid.

External resources

External resources are those resources that lend support beyond family and friends and consist of professionals such as physicians and psychologists, support groups, organizations, and agencies which can assist the parents and children in learning more about the disability and interventions available.

Levels of functioning with children who have autism

Because autism is a spectrum disorder it is necessary to define functionality as it applies to the children in this study. For the purpose of this study, low functioning children are defined as ones who exhibit significant behavioral problems such as self-injurious behaviors and harm to self or others such as biting, hitting, or kicking. Low functioning children have little or no speech, little or no eye contact, and severe social impairments such as being tactile defensive or avoiding others. Low functioning children with autism may also have intellectual
deficits to the extent they require a self-contained classroom. Those children with autism who are high functioning are considered to be under stimulus control, following directions, having at least some degree of speech and communication, have tolerance of others, and can often be educated in a regular classroom.
CHAPTER TWO

REVIEW OF LITERATURE

While reviewing the literature, it was apparent that the field of autism has generated more interest over the past several years. Many facets of autism have been investigated including the stress and coping abilities of parents who have a child with autism and the daily struggles they face. For example, Sanders and Morgan (1997) looked at the family stress associated with having a child with a disability, while Kasari and Sigman (1997) examined the perceptions parents have about their child with autism. When investigating the stress and coping strategies used by parents who have a child with autism, it is essential that a thorough investigation be done. The current review of literature includes the stress of parents with typically developing children as well as parents who have children with disabilities such as learning and physical disabilities. The review also includes research regarding coping strategies used by parents in raising a child regardless of their developmental progress.

Life Event Stress

Defining stress

According to Robson (1999) the term stress can be used to describe an emotional state, a physiological condition and in some cases it can be used as a synonym for "strain." According to Robson most people perceive stress as anxiety, frustration, and conflict that can produce a pathological change in behavior. Stress is something that cannot be avoided.
Methods of measuring stress

Stress can be measured in a variety of ways such as standardized tests or interviews. There are many standardized tests that were designed for the sole purpose of measuring stress levels. The Parenting Stress Index (Abidin, 1990) is one of those instruments. The Parenting Stress Index measures the two major domains of stressors: child characteristics that increase parental stress, and parent characteristics that increase parental stress. An interview is another way of attaining information about stress by asking an individual questions regarding the origin of his/her stress and how it is managed. Miller and Smerglia (1998) stated that the method in which stress is measured may play a big part in the reported stress level of an individual. Some professionals feel that many evaluation methods measure stress additively. This may happen when there is more than one stressful event that occurs near the time of another one. There is also a notion that a stressful event may cause other stressful situations. For example, if a death occurs, there is not only the stress from losing a loved one, but also the financial changes that may incur, thus producing more stress for the individual. Some stress measures may not take into account that all life events which produce stress are not equally stressful. For example, taking an exam in school does not compare to the stress one feels when there is a death in the family.

Many questions can be raised about the instruments used to measure stress. Some of the instruments have not been normed on parents who have a child with a disability. One cannot assume that the measure used to assess stress in parents who do not have a child with disabilities can generalize to those parents who do have a child with a disability. Although norms should be used that include parents who have a child with a disability, more frequently norms are used which are simply available (Abidin, 1990).
**Causation of stress**

Although past research clearly shows that parents who have a child with a disability have higher levels of stress than those parents without a child with a disability (Boyce & Behl, 1991; Dyson, 1996; Margalit & Ankonina, 1991) it is unknown whether the stress is caused from parental factors or child factors. Innocenti and Kwisun (1992) reported that needs which go unmet cause high levels of stress in families.

**Coping with stress**

Research conducted by Margalit and Ankonina (1991) revealed two different patterns concerning the research on stress: stress which results in pathology, and stress resistance which involves coping skills and overall climate of the family. The latter places more emphasis on a family’s ability to stay healthy during the presence of stress which may lend itself to an effective coping strategy. Stress which results in pathology are those stressors which are repressed or go unaddressed by the individual therefore creating a situation in which the individual does not cope with his or her stress, therefore worsening their condition. Stress which may not result in pathology requires the use of effectively coping. Margalit and Ankonina (1991) reported that families of children with a disability used more avoidance as a coping strategy and felt more stressed than those parents with typically developing children. They found that parents of children with a disability placed significantly less emphasis on the relationship of the family and had less occasion for personal growth. Their results indicated that parents who used coping strategies had stronger stress resistance than those parents who did not. Dyson (1996) conducted a similar study on 30 families who had one child with a disability and one typically developing child and found that the presence of a child’s disability increased stress levels of parents.
According to Innocenti and Kwisun (1992), there is a “normality” approach which emphasizes all families have stress, and that resources should be explored for everyone to help mediate this stress. In working with families who have children with disabilities, the approach which accommodates the intent of P.L. 99-457 is “normality” (Innocenti & Kwisun, 1992). This approach lets the family know that experiencing stress is normal, but coping strategies must be used to help manage it. According to Trivette, Dunst, Deal, Hammer, and Propst (1990), the “normality” approach is not always emphasized by today’s interventionists. Rather many interventionists assume that a child with a disability causes high levels of stress and dysfunction in families. According to Innocenti and Kwisun (1992) there are many reasons why interventionists take this approach to the stress factors which families experience. First, it takes a lot of time to research family functioning. Second, professionals usually focus more on intervention than on coping strategies that may be more helpful to the parents. Finally, the way in which stress is measured can sometimes lead interventionists to believe stress is a problem area instead of realizing it occurs regardless of our attitude about it.

Coping strategies

There are many strategies one can use to cope with stress. The cognitive-phenomenological approach to stress emphasizes that the amount of stress one experiences is directly related to the coping strategies used (Guess, 1998). Holahan and Moos (1985) found the more successful coping strategies used, the more adaptable one becomes while developing higher tolerance in stressful situations. The authors research revealed that individuals undergoing a great amount of stress who used more avoidance coping were more likely to experience physical or emotional distress. Examples of avoidance coping
strategies are behaviors such as putting off thinking about something or repressing the events may cause a person to become more psychologically distressed.

Coping requires thought about the decisions that need to be made to help alleviate stress. Those thoughts and decisions can be influenced by moods, emotions, and reactions that each individual incurs from stress and can be either negative or positive in nature (Miller & Smerglia, 1998). These decisions also play a significant role in the ability to cope and adapt to specific situations. For example, when an individual is sitting in heavy traffic, knowing he/she is already late to an appointment, coping strategies must be utilized to make a decision about what to do: for example, take another route, use a cell phone to let the person know, or sit in the car and blast the horn.

Parental Stress in Families who have a Child with Autism

Parent perceptions and beliefs about autism

The way in which a person manages stress often comes from their beliefs and perceptions about specific issues, so it is important to address those beliefs. In 1997, Kasari and Sigman examined the behaviors of parents who had a child with autism. The researchers also looked at the perceptions of these parents and level of child functioning in relation to parental stress levels. There were 28 children with autism, 26 children with mental retardation, and 28 typically developing children in the study. The Parenting Stress Index (Abidin, 1990) was utilized to measure parental stress. As hypothesized, parents who believed their child to be more difficult to handle were less engaged with their child and reported higher stress levels. In previous studies (Bristol & Shopler, 1984; Koegel et al., 1992) parents of children with autism reported greater stress and depression when the child was lower functioning. In this study, the
developmental ability of the child with autism was not found to directly affect the level of stress the parents experienced. Kasari and Sigman found that parents of children with autism and mental retardation reported their children as more temperamental and felt higher stress levels than the parents with typical children. In 1999 Haussier conducted research on parents’ attitudes and experiences regarding treatment for children with autism world wide. Thirty-two parents of children with autism participated in the study. Her goal was to explore the attitudes of parents and their receptivity to different treatment approaches, specifically the TEACCH (Treatment and Education of Autistic and related Communication handicapped CHildren) program in North Carolina. Parents in three areas of the world were administered structured interviews to assess the etiology of their child’s autism, locus of control related to improvement, experience of their collaboration with professionals, and other specific information related to the TEACCH model. Haussier found parents attitudes to be geographically different (North Carolina, Germany and Denmark). The United States and Danish parents believed the etiology of their child’s autism to be organic in nature. People from three areas had high involvement in their child’s intervention and were primarily concerned with their child’s social competency. Those participants from Denmark and North Carolina tended to be satisfied with the collaboration they had with professionals. The German parents believed the etiology to be psychosocial in nature and were dissatisfied with the collaboration between parents and professionals.

Castle (1998) conducted a study about parental feelings and grief when having a child diagnosed with autism and other pervasive developmental disorders. The goal was to assess whether these parents experienced grief when they found out their child’s diagnosis. The study involved 29 parents whose children had been diagnosed with autism or pervasive developmental
disorder. Results revealed that grief reactions were similar to those found in people who have lost a loved one.

**Parental stress and adjustment**

In 1996 Bundy investigated the relationship between adjustment and stress in parents who have children with autism. The participants included 50 mothers and 27 fathers of children with autism. Mothers and fathers rated the things they perceived to be stressful differently from one another. Parents differed in how stressful they felt the characteristics of their children were. For example, mothers felt the most stressful part of parenting a child with autism was how difficult the child's behaviors were, while fathers felt that the atypical social behavior of their child was more stressful. Parents also disagreed on the stress levels associated with age of the child. Some parents felt that more stress is associated with a younger child with autism while other parents felt that it was more stressful as the child got older. Results indicated that perceived stress associated with having a child with autism may have a direct impact on the adjustment of a parent.

Sanders and Morgan (1997) conducted a study about parental stress and adjustment in three types of families; those who had children with Down syndrome, those who had children with autism, and those parents having typically developing children. Fifty-four families participated, with 18 representing each of the three groups. Stress was measured using the short form of the Questionnaire on Resources and Stress (Friedrich, Greenberg, & Crnic, 1983). To assess family adjustment, the Family Environmental Scale was used, which is a 90 item true-false measure of social and environmental characteristics (Moos & Moos, 1981). The study focused on assessing whether parents of children with autism, Down syndrome, or typically developing children differed significantly
with regard to levels of stress. Results revealed that both fathers and mothers of children with autism perceived themselves as having significantly more stress than those who had children with Down syndrome followed by parents of typically developing children. Parents of children with autism perceived higher rates of stress than the other two groups in areas such as finding a babysitter, and having free time. Parents of children with autism and Down syndrome indicated more pessimism about the future of their child, especially as they reach adulthood. Parents of children with autism reported more concern than the other two groups with regards to behavioral problems such as self-stimulatory behaviors, aggression, undesirable sleep patterns, and hyperactivity. Overall, the parents who had children with autism voiced the strongest opinion that their child had negative characteristics. Results also revealed that parents of children with autism were less likely to engage in events and activities in society because of the negative characteristics of their child such as self-stimulatory behaviors and lack of social awareness. Overall, parents of children with autism have more family stress and adjustment problems than parents of typically developing children.

In 1998, Guess investigated the stress and coping abilities of parents with children who have autism, mental retardation, and children without disabilities. Fifty-three parents served as subjects for this study: 18 parents of children with mental retardation, 17 parents of children with autism, and 18 parents of children without disabilities. The purpose of the study was to assess coping strategies and perceived stress of parents of children with and without disabilities. Parents were administered the PSI and Ways of Coping Scale to measure stress and coping efforts of all groups. The Ways of Coping Scale is an assessment tool that measures the coping efforts of parents and is broken down into emotion-focused coping and problem-focused coping. An interview was conducted to
determine similarities and differences among both sets of parents. Results indicated that stress was a function of the parents' inability to cope with their child with a disability, rather than the stress from the child's condition. Results revealed that there was not a statistically significant difference in total stress between the parents of children with autism, other disabilities or typical children. Results on the Ways of Coping Scale revealed that there was no significant difference between the three groups. That is, no one group used emotional coping over problem-focused coping strategies.

In 1998, Brown-Godsavé conducted a study about adjustment in parents of children with autism. The Parenting Stress Index was administered to fifty mothers of children with autism. Results indicated that the mothers considered themselves to be successful in their parenting roles, however, they considered their family to have significant stress. The mothers also reported that their family was well adjusted even with the added stress of having a child with a disability. The author also found that the more severe the autism, as reported by the mothers in the study, the higher levels of parental stress and lower levels of family social integration. Also, a higher degree of external locus of control was predictive of higher levels of parenting stress. That is, parents who felt that the disability was not in their control reported higher stress than those parents who believed they had control over the disability.

In 1996 Shorten evaluated parents of children with autism who were involved in behavioral intervention, coping strategies, stress factors, and perceived locus of control. Participants in the study included 16 parents who had a child diagnosed with autism. The ages of the children with autism ranged from 18 months to six years. A packet was sent to parents including the Parenting Stress Index, the Questionnaire on Resources and Stress-Friedrich, the Parental Locus of Control Scale, a demographic questionnaire, and a time survey. Follow-up
phone calls were made by the researcher to answer any questions regarding the study. Results indicated that parents of children with autism were significantly more stressed than other parents. Shorten used the Questionnaire on Resources and Stress to investigate parents' perceived coping abilities. The results showed that parents who used a religious group as a support system for coping felt less socially isolated from the world. Parents also felt their child to be less demanding as length of time in an intervention increased. Results revealed that parents with higher socioeconomic status created more resources and managed their stress better than those parents with low socioeconomic status. Over the course of the program, parents with higher socioeconomic status and education changed their beliefs from external to internal locus of control. Though many assessments tools were used for this study, more information was gained regarding resources for coping in the interview portion of the study.

In 1999 Dewey conducted a research study on 104 parent pairs who had children with autism. The purpose of the study was to investigate the stress of parents who had a child with autism. He developed a survey instrument that was based on the Childhood Autism Rating Scale (CARS) and modified it to evaluate the stress associated with each symptom of autism. Dewey found that parents who had children with autism were significantly more stressed than those who had typically developing children. Both mothers and fathers rated stress levels the same. Parents reported different stress levels depending upon the age and behavior of the child. No significant differences were found on parental ratings of symptom severity. There was also no significant difference found between the gender of the child and level of stress.

According to the review of literature, parents who have a child with autism experience more stress than those parents of children with other disabilities and those with typically developing children. Although Brown-Godsave (1998) found
that parents who have lower functioning children have more stress than those parents who have higher functioning children with autism, this was disputed in the research done by Kasari and Sigman (1997), who found no significant differences between the groups. Parents of children with autism also had more pessimism about the future and more concern about behavioral problems in their children resulting in parental withdrawal from social events and activities. Most studies showed that parents who had a child with autism associated negative characteristics with their child. Only one study was conducted regarding perceived stress levels in fathers as opposed to mothers and results indicated that fathers typically reported less stress from having a child with autism than mothers (Bundy, 1996).

Results of these studies revealed that internal coping strategies such as family members and church family were utilized most frequently. Research also indicated that those parents in higher socioeconomic groups created more resources for coping although these specific resources were not identified.

Parental Stress with Families who have a Child with a Disability Other than Autism

The assumption should not be made that a parent who has a child with autism experiences the same stress of a parent with a child with other disabilities. For this reason it was necessary to review literature specifically associated with parents of children with disabilities. Boyce and Behl (1991) conducted a study about parental and child stress in families with and without children with disabilities. The authors obtained their data from a series of studies conducted by the Early Intervention Research Institute. A total of 479 families who had children with previously identified disabilities were given a variety of self-reported measures. Ninety-seven percent of the measures were completed
by the mother. Eighteen percent of the families in the study had more than one child with a disability. The independent variables were family demographics (age, ethnicity, income, and education), family processes (support, resources and stressful life events), and child characteristics (child's age, gender, health and level of functioning). Many instruments were used to assess the variables: Parenting Stress Index, The Family Inventory of Life Events and Changes, The Family Adaptability and Cohesion Evaluation Scales III, The Family Resource Scale, The Family Support Scale, The Report of Child Health, and The Battelle Developmental Inventory. Results revealed that parent related stress was at the 62\textsuperscript{nd} percentile and child related stress was at the 80\textsuperscript{th} percentile for parents who had a child with a disability. Scores on social support were within normal limits as were general resources, time availability, and stressful life events when compared to most families however, the parents of children with a disability in the study still reported elevated parent related and child related stress. Results also revealed that older mothers with more education and income, living with their spouse reported less child related and parent related stress than those mothers who were younger and had less education. Those mothers who had a greater number of children and had more than one child with a disability reported more stress. Overall, the more support and resources utilized by the parents, the less stress they reported experiencing. Income and level of functioning of the child was not a significant predictor of parental stress. According to the results from the Parenting Stress Index measurement, parents of children with disabilities have a higher level of stress compared to parents of children without disabilities. The functioning level of the child produced stronger child related stress than the other variables. Stressful life events were the strongest predictors of child related stress. As expected, those families who had more than one child
with a disability experienced higher stress levels than those with one or less child with a disability.

In 1996, Dyson conducted a study on parental stress of children with learning disabilities. Thirty families who had one child with a learning disability and one typically developing child participated in the study consisting of children from ages 7-14. Questionnaires and interviews were conducted in the families' homes and 84% of the questionnaires were completed by the mother. The comparison group consisted of 55 typically developing children from ages 7 ½ to 14 ½. The author used The Questionnaire on Resources and Stress-Short Form (QRS-F; Friedrich, Greenberg, & Cmic, 1983). This instrument assesses the influence of an illness or disability on family members. The higher the scores, the higher the stress level of the parent. There were two interview questions following the completion of the instrument in which the parents were asked about any problems their family experienced due to their child's disability, including those regarding siblings and school. The results indicated that the presence of a child's learning disability increased stress levels of parents. The results also suggested that family routines and sibling interactions were somewhat altered compared to those families without a child with a disability.

Innocenti and Kwisun (1992) conducted a study which examined issues regarding parent-oriented and child-oriented parenting stress using the PSI. The study compared samples of children with disabilities to the PSI normative data found in the PSI manual. The authors had three primary questions they addressed: 1) How do scores mothers who have a child with a disability compare to the PSI normative sample in parent and child stress? 2) Do scores reported by mothers who have a child with a disability represent a normative distribution? 3) What are the items mothers most often report as being stressful in the area of child-related stress? The data on the families with disabilities were obtained from
the Early Intervention Research Institute's longitudinal studies. Disabilities ranged from physical impairment such as deafness, blindness and cerebral palsy, to other disabilities such as mental retardation, developmental delays and learning disabilities. Parents of 725 children with disabilities participated in the study. All demographics for both samples were approximately the same. The ages of the children ranged from 1 month to 74 months. The Parenting Stress Index was used to assess parental stress and was completed by the mothers of the children. Results revealed that there were not significant differences between any of the normative data and the comparative data except that parents of children with disabilities less than twelve months old reported significantly less child related stress than the normative group. The results also revealed that parents who had a child with a disability reported more stress on the child domain, however, no differences were found on the parent domain except for the age three comparisons. Parents who had three year olds with a disability reported more stress than the normative sample of three year olds.

In 2000, Baxter, Cummins, and Yiolitis reported on a longitudinal study on parental stress with parents who had a child with a disability and parents who had typically developing children. The study was done over a seven year period and assessed parental worry in having a child with a disability and amount of stress attributed to the youngest sibling without a disability. The aim was to identify the relationship between parental worry and the stress parents attributed to their child with a disability over time. The initial sample included 131 parents which consisted of 60 parents of 3-5 year old children, 35 parents of 10-12 year old children, and 36 parents of 17-19 year old children. During the second set of interviews seven years later, a smaller sample was utilized due to the number of families the researchers were unable to contact. This interview consisted of 93 parents which included 44 parents of 10-12 year olds, 29 parents of 17-19 year
olds, and 20 parents of 24-26 year olds. Parents in the study were interviewed in their home by two interviewers who were assigned to mothers or fathers alternatively. For the purpose of this study, stress was defined as "parent-perceived" and recorded on a five point Likert scale which consisted of "very great stress" (5), "considerable stress" (4), "some stress" (3), "little stress" (2), and "no stress" (1). Parents were asked how much stress they experienced as a result of their family member with a disability. The parents were asked to circle the number on the scale which came closest to the amount of stress they incurred. Parents were also asked how much stress they felt they were experiencing as a result of their youngest child without a disability. These same questions were also asked during the second interviews. Results of this study revealed that parents rated themselves as having significantly more stress with their child with a disability than their youngest child without a disability.

Young and Roopnarine (1994) investigated fathers’ involvement with children with and without disabilities and the stress it puts on their marriage. Twenty-three two-parent families who had a child with a disability and 24 two-parent families with a typically developing child participated in the study. The mean age of the children was approximately 3.85 years for both groups. The authors attempted to assess whether there were differences in marital stress between fathers who had a child with a disability and those who did not. The children with disabilities were separated into three categories based on their diagnosis of autism, language delays and other disabilities (Down syndrome, cerebral palsy, and physical disabilities). Over 95% of the spouses of fathers of children without a disability worked outside the home, but only 45% of the spouses of fathers who have children with a disability worked outside the home. Each parent filled out the Paternal Involvement in Child Care Index (Radin, 1982); the Family Functioning Style Scale (Deal, Trivette, & Dunst, 1988); the Personal Network Matrix (Dunst,
Trivette, & Deal, 1998); and a Measure of Martial Stress (Pearlin, 1975). Results indicated that stress levels in both families were low. Results of this study revealed that the involvement a father has with his child was similar regardless of whether the child had a disability.

Overall, the research results revealed that parents with children who have a disability had more child related stress than parent related stress. The research also revealed that older mothers with more education reported less stress and those who used resources reported having less stress. Literature indicated that there were more problems between siblings than in families without children with disabilities (Dyson, 1996). Research results were consistent in showing that parents of children with disabilities perceived themselves to have more stress than those parents who had typically developing children with the exception of one study (Christenson, 1990) that found no differences in stress levels. As Dyson (1996) noted, further research needs to be done to discover the sources of stress parents experience. Research also consistently revealed that those parents who had one child who is typically developing and one child with a disability associated significantly more stress with the child with a disability.

**Coping Strategies of Parents Who Have a Child with a Disability**

According to Judge (1998), there are several forms of coping strategies such as problem-focused coping which includes problem solving and social support. For example, in a stressful situation, a parent may choose to attend a support group, talk to a friend, or solve the problem by focusing on a positive outcome solution. Another coping strategy is emotion-focused including staying away from a particular stressful situation, controlling one's feelings, or placing blame on oneself for the particular circumstance. Judge stated there are a variety of definitions that have been used in research on coping such as efforts to manage
stress, alteration of the events that cause stress and making efforts to control the emotional state which occurs as the result of a stressful situation. Another definition used for coping is the changing of an individual’s thought process and behaviors to manage stressful life events for which a person does not have adequate resources to otherwise manage them.

In 1991 Margalit and Ankonina investigated the positive and negative affect and coping abilities of parents with children who were disabled. Parental affect, both positive and negative, family climate, and coping strategies (active and avoidant) were measured for 71 families of children with disabilities. These families were compared to 77 parents who had children without a disability. The goal of their study was to examine stress resistance resources for parents who had a child with a disability. The focus was to discover elements that predicted positive and negative affect. The children with disabilities included 45 males and 26 females. Their disabilities included 38 children with learning disabilities, 21 children with mental retardation, and 12 children with emotional and behavioral disorders. The Coping Scale was used to evaluate parents’ view of their own coping abilities and strategies. The Child Behavior Checklist was used for evaluating parents’ perceptions of their child’s functioning and to investigate whether the functioning and type of disability impacted the parents’ stress levels. The questionnaires were administered in the home of the parents. Results of the study indicated that fathers and mothers of the children with disabilities placed significantly less emphasis on the relationship of the family and felt they did not have the opportunity for personal growth in the family. Margalit and Ankonina also found families of children with disabilities used more avoidance as a coping strategy and had more negative affect than those parents of typically developing children. Parents who did not have a child with a disability had greater positive affect as predicted. They achieved this by using active coping, focusing on family
relationships, and finding opportunities for personal growth. As an attempt to investigate stress resistance, the authors wanted to assess parents negative and positive affect and its predictors. Results indicated that parents who used an active coping strategy had a stronger stress resistance and greater positive affect. Greater family resources were also components which predicted positive affect in parents. In the families without a child with a disability, neither active coping strategies or family support predicted positive affects of parents. Boyce and Behl (1991) found that parents who had a child with a disability who used coping strategies for their stress still reported significantly higher stress levels than parents without children with disabilities.

In 1998, Judge investigated the strengths and coping strategies in parents of children with disabilities. She investigated the relationship between the strengths of the family and the perceptions of coping strategies which the parents perceived they used. Sixty-nine parents (88% mothers) who had a child with a disability participated in the study. The participants had children from birth to age five and consisted of 68% boys and 32% girls. Most of the children had a previous diagnosis of a disability and were considered developmentally delayed or at-risk for developmental delay. The participants completed the Ways of Coping Questionnaire (Folkman & Lazarus, 1998). The questionnaire contains several coping strategies which people use to help manage difficult and stressful situations. Using a 4-point Likert scale, parents indicated the extent to which they used the specific coping strategies on the questionnaire in a recent stressful situation. The Family Hardiness Index (McCubbin, McCubbin, & Thompson, 1991) was also administered to participants to measure the strengths of a family during a stressful life event such as working together as a family, ability to count on one another, the ability to be proactive, and having confidence as a family to overcome the situation. Results revealed that parents used a number of different
strategies to cope with stressful events. Fifty-eight percent of the strategies parents used for coping were problem-focused such as asking a friend or relative for advice or talking to someone else to attain more information. The most frequent coping strategies parents reported using were concentrating on what to do next and on the necessity to make things work. Parents also reported using external social support and viewing the difficult situations in a positive manner, making sure everyone involved came out doing well. There was a positive relationship between parental coping strategies and family strengths. The more a parent used social and emotional support, the more strength the family had to manage their situation, thus using internal resources as a coping strategy.

Cameron and Armstrong-Stassen (1991) investigated stress and coping abilities in mothers of adults with developmental disabilities. The purpose was to examine the stress mothers experienced and the strategies mothers used to cope with their difficult situation. One hundred and forty seven mothers of adults with developmental delays participated in the study. Of all participants in the study, 105 of the children still lived at home. Each participant completed a questionnaire on resources and stress to measure the impact of the child with a disability on the mother. The participants also filled out a questionnaire about coping abilities which measured the social, psychological, community, and financial resources available for managing stressful situations. Results of the study indicated that mothers of children who exhibited more behavioral problems reported higher stress than those mothers whose children did not have behavioral problems. However, mothers of children with more handicapping conditions such as physical handicaps or severe medical conditions had scores which were not different from the mothers who reported their child to have a mild disability. Resources and financial well being were negatively related to mother's stress. Mothers who felt they were financially secure, in good health, and had a
greater sense of mastery reported having lower stress. Mothers who reframed their stressful events to make them more manageable reported lower stress. When mothers felt they had control over daily life events, less stress was reported. When mothers used the coping strategy of acquiring support from their family or friends, there was significantly less stress reported.

Hanline and Daley (1992) examined family coping strategies and the strengths in Caucasian, African-American and Hispanic families of young children. The purpose of the study was to investigate the relationship between mother’s perceptions of family coping strategies and strengths in families with and without children with disabilities. Participants included 206 mothers of children 36 months old or less. Twenty-nine percent were Hispanic, thirty-two percent were African-American, and thirty-nine percent were Caucasian. Approximately 60%-70% of the participants in each group had a child with a disability. The disabilities included sensory impairments, neurological problems, genetics disorders, physical disabilities, and developmental delays. Two self-reported measures were used including the Family Crisis Oriented Personal Evaluation Scales (Olson, McCubbin, Barnes, Larsen, Muxen, & Wilson, 1985) which measures problem solving abilities, and the Family Strengths Questionnaire (Olson et al., 1985), which measures perceptions of respect, trust, and loyalty within the family. In all ethnic groups, internal coping strategies tended to be more predictive of family strengths than external social supports. Minimizing reactivity (minimizing the problem in ones mind) was negatively related to family accord in children with and without disabilities in Hispanic families. Although minimizing may help the families to handle their problem, it had a negative impact on the families sense of mastery. Some families used passive appraisal as a coping strategies in difficult times, thus delaying the thought of the problem. Passive appraisal includes relying on luck, hoping the
problem will go away, and engaging in other activities to avoid thinking about the problem. Receiving outside support positively predicted family strength in only two groups, but the authors stress that this should not preclude professionals from referring families to outside resources nor does it suggest that these families could not benefit from outside support. This finding may also indicate family preference in using internal or external support. Caucasian families who have children with disabilities reported using coping strategies of minimizing reactivity, social support, spiritual support, and mobilizing the family to attain resources more than caucasians without children with disabilities. Although more coping strategies were used in families who had a child with a disability, mothers still reported less family pride. Families who had a child with disabilities utilized social support to a great extent. Although parents in this study reported positive outcomes from having a child with a disability, overall results revealed that having a child with a disability affects family functioning and stress to a great degree.

Overall, research findings indicated parents who used avoidance strategies for coping had more negative affect than those parents who used active coping strategies. Parents who used active coping strategies felt less stress than those parents using avoidance coping strategies. Parents who reported using family resources had more positive affect than those who didn't. Literature results showed a positive relationship between family strengths and parental coping styles. Research indicated that parents who had a child with a disability used internal coping strategies such as getting advice or talking to a friend. Research revealed that internal coping strategies were used more than external ones. Research was not done on the specific internal and external resources used and which resources were most beneficial to parents. Many parents also focused on what steps to take next in coping with their child. Mothers reported that they felt
lower levels of stress when they used reframing such as finding new and positive ways to deal with their stressful life event. One author found that families of higher socioeconomic status created more resources to manage their stress than those families who were of lower socioeconomic status. This author also reported that both marital and outside support groups were common resources used.

Summary

According to the review of literature, parents who have a child with autism experience more stress than those parents of children with other disabilities and those with typically developing children. Although few articles were found regarding functionality of the children who had autism, findings regarding the relationship between level of child functioning and parent stress levels were mixed. Higher stress levels were reported for some parents with children who had more behavioral problems. However, other studies reported no difference in parental stress levels and functioning of the child. The literature was consistent in reporting that parents of children with autism had a tendency to withdraw from social events and activities. A single study describes how fathers and mothers differ in their perceived stress levels (Bundy, 1996). Literature revealed that parents of children with autism have more overall stress and more stress related to marriage and siblings in their families. Research identified more child related stress (age, functioning level) than parent related stress (lack of support and resources). Research results were consistent in showing that parents of children with disabilities perceived themselves to have more stress than those parents who had typically developing children with the exception of one study (Christenson, 1990), which found no differences in stress levels. Research also consistently revealed that those parents who have one child who is typically...
developing and one child with a disability has significantly more stress with the child with a disability.

When examining stress and coping strategies of parents who have children with disabilities, research clearly indicates that parents who used an active approach to stressful situations had more positive affect than those who used avoidance coping strategies (Margalit & Ankonina, 1991). Although some parents may deny their stressful situations thus using avoidance as their coping style, more negative affect is typically presented by the parent. Parents who had a child with a disability had more positive affect by using active coping, focusing on family relationships, and finding opportunities for personal growth.

Overall, the literature regarding coping abilities indicated that parents who used avoidance strategies for coping had more negative affect than those parents who used active coping strategies. Parents who used active coping strategies felt less stress than those parents using avoidance coping strategies. Parents who used more family resources had more positive affect than those who didn’t use a family member for a resource. Literature was lacking in the different coping styles and strategies used and few studies were found regarding the types of resources which were used in coping with a child with autism.

There was a trend in the research that revealed more internal coping strategies were used than external ones. Research was not done on the specific internal and external resources used and which resources were most beneficial to parents. Mothers’ reported that they felt lower levels of stress when they tried new and positive ways to deal with their stressful life event. It was also reported that both marital and outside support groups were common resources used. No articles were found regarding the coping strategies of mothers and fathers individually or which resources each parent thought to be most beneficial.
CHAPTER THREE

METHODOLOGY

Human Subjects Approval

Previous to any data collection the Human Subjects committee signed an approval for the study (Appendix D).

Subjects

The subjects in this study were thirty parents of children with autism, fifteen mothers and fifteen fathers. At least one parent in each family had a child who has previously been diagnosed with autism. The ages of the children with autism were from two to eight years old. The control subjects consisted of fifteen fathers and fifteen mothers of typically developing children between the ages of two and eleven. Subjects were recruited from one Midwest community, one eastern community, and one Western community in the United States. The participants included seven married couples with children with autism who lived in the western region of the United States, and seven married couples with children with autism who lived in the midwest region of the United States. The fourteen married couples were the biological parents of the children with autism. The other two subjects consisted of a single parent of a child with autism, and one step parent. All participants interviewed in the control group were parent pairs married to each other. Twenty-seven percent of the control group lived in the midwest, twenty percent lived in the eastern region of the United States, and seven percent lived in the western portion of the United States. For purposes of
this study, all subjects who have a child with autism will be referred to as “group one,” and the control group will be referred to as “group two.”

Because of the limited population of children with autism, group one was obtained through a convenience sampling of willing participants who had a young child with autism. Although there were originally 35 participants in group one, two participants dropped out of the study, so three more were eliminated to give an even number of thirty participants with children with autism.

The control group consisted of thirty participants to match the number of participants in group one. Forty names were solicited from professional colleagues of the researcher for group two. The forty people on the list were then called to ask if they would participate in the study. Thirty-four participants agreed to participate in the study, however four were eliminated so there would be an equal number of participants in each group.

All children in the study who have autism have been previously diagnosed by a professional such as a neurologist, psychologist or family physician. The children with autism fit within the criteria determined by the Diagnostic and Statistical Manual- 4th edition (American Psychological Association, 1994).

Data Collection

All participants were called by the researcher to explain the study over the phone. All participants received a packet by hand delivery or by mail depending on their locale. Participants proximate to the researcher, those in the midwest, received packets by hand. The participants who received the packet in the mail also received a phone call after they had time to receive the package and read the materials. The packet included a letter which stated the purpose of the study, a consent form which stated the study was strictly voluntary and they could choose to disengage at any time, the methods of the study, and the
benefits and risks to the participants (Appendix A). The demographic questionnaire, PSI booklet and answer sheet, and the CISS were also included in the packet. Group two was only administered the CISS, PSI and demographics questionnaire. This group was not given an informal interview as most questions on it related to autism and resources used on behalf of the child with autism.

In group one, sixteen of the participants filled out the questionnaires and were interviewed face-to-face (Appendix C). Fourteen of the participants filled out the questionnaire on their own and received a phone call for interview. For those participants with whom a face-to-face interview was conducted, all materials were completed at that time. For those who received phone interviews, the materials were sent to the participants initially and one week elapsed before the phone interview was conducted. At that time, the participants were asked to mail all materials back to the researcher in the self-addressed, stamped envelope provided for them. A follow-up phone call was given to those participants who did not send their package back within two weeks. With the exception of two individuals, all participants agreed to complete the materials.

Measures

Coping inventory

A measure entitled the Coping Inventory for Stressful Situations, Endler and Parker (1999) was used in the current study to examine how people react to stressful situations. It is a measurement of parents' views regarding their own coping strategies when placed in stressful situations. The scale consists of 48 items which investigate avoidance coping and active coping. The questionnaire is scored on a 5-point Likert-type scale. Answers to the items range from "not at all" (1) to "very much" (4). Higher scores indicate a parent's belief that they use a
particular coping strategy. The CISS has five scales: task coping, emotion coping, avoidance coping, distraction coping, and social diversion coping. Task coping includes being organized, adjusting one’s priorities, taking immediate action, and focusing on the problem. Examples of emotion-oriented coping include getting angry, taking stress out on others, and not knowing what to do about the situation. Avoidance-oriented coping involves watching television, taking time away from the situation, going for a walk, and sleeping. Examples of distraction-oriented coping include going shopping and wanting to sleep. Social diversion coping includes phoning a friend, getting advice from others, attending a party, and spending time with a special person. The Coping Inventory was normed on 2081 adults and 817 adolescents. It yields five raw scores for coping which can then be translated into percentile scores. The Coping Inventory has test-retest correlations broken down by gender and coping scales and are shown in table 3.1.

Table 3.1

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To increase validity of the CISS, it is presented to participants as a measure of reaction to various stressful situations. Many respondents want their responses to be socially desirable and are likely to answer questions accordingly. To minimize the effects of social desirability responses, respondents should be assured about the confidentiality of their scores (Endler & Parker, 1999).

**Parental stress**

The Parenting Stress Index (PSI) (Abidin, 1983) is an assessment used to measure the amount of stress a parent is experiencing. The assessment tool measures two major domains of stressors in the parent-child relationship which are child characteristics that increase parental stress and parent characteristics that increase parental stress. Because the total stress score on the PSI is a combination of the parent and child domain, the total score was not used for the purpose of this study. As Boyce and Behl (1991) reported in their study, although it is clear that parents of children with autism report higher stress than parents without children with autism, it is unknown whether the stress is parent or child related. For this reason, it was the intent of the researcher to investigate what domain the stress is coming from parent or child.

The PSI consists of seven subscales measuring different types of relationships and parental functioning: 1) social isolation, 2) depression, 3) restriction of role, 4) attachment, 5) relationship with spouse, 6) parent health, and 7) sense of competence. There are also six sub scales which measure child and child-parent relationship characteristics: 1) mood, 2) what reinforces parents, 3) adaptability/stability, 4) acceptability, 5) distractibility and hyperactivity, and 6) demandingness. The PSI was normed on 2,633 parents and is usually completed by the mother. The Parenting Stress Index yields a total stress raw
score from two scales: child characteristics and parent characteristics. The raw scores can then be converted into percentile scores. According to Abidin (1983) it is possible for parents to earn a score in the 15%-80% percentile and still fall within the normal range for stress. The PSI can be used for parents of children up to 12 years old but Abidin (1983) reported that it is specifically designed for preschool children. A number of studies have investigated the stability of the PSI indicating the test-retest coefficients for the child domain is .77 and .88 for the parent domain (Boyce & Behl, 1991).

Innocenti and Kwisun (1992) recommended that the normative table used in their study also be utilized along with the ones provided in the PSI manual when working with other children with disabilities as it is the largest sample size at the time their research was conducted. The authors felt that their data represented a more diverse sample than is typically available on norm-referenced measures for families. It may be a more accurate gauge of stress that a parent who has a child with a disability presents. Using these norms may provide helpful information in realizing that the stress parents experience is not necessarily abnormal.

**Demographics**

A demographic questionnaire was designed by the researcher which surveyed participants' marital status, age, education, ethnicity, yearly income, type of community lived in, number and ages of children in the family, age, gender and birth order of the child with autism, and age of the child when diagnosed with autism. The control group filled out the same demographic questionnaire with exception of filling out the last four questions which asked about information regarding autism (Appendix B).
Interview

A short semi-structured interview was given to each participant in group one. Questioning included the stress participants were currently experiencing, resources participants were currently using to reduce stress associated with their child with autism, the typical day of their child, and questions about other interventions being used (Appendix C). The questions regarding the stress associated with autism reported in the interview were categorized from the parents' actual responses. For example: if a parent reported stress related to their child kicking, hitting, and screaming, it was reported as "behaviors," if a parent reported that stress came from the child not talking or communicating, it was categorized under "language barrier." Responses were analyzed and placed into eight possible categories: "behavioral problems," "language barrier," "financial burden," "sibling concerns," "finding therapy," "school problems," "locating a baby-sitter," and "health concerns."

Feedback to Participants

All participants were given the opportunity to receive findings of the research after the study is completed. The feedback will consist of the combined, analyzed data and will not be the individual data of any participant. Results will be sent to those participants requesting it within four months of the completed dissertation.

Risks

Although it is possible that some of the study questions may have brought about worry, or negative feelings about raising their child with autism, local agencies were available should any of the participants need to talk about or cope with these issues. None of the participants required the referral.
Benefits

A possible benefit was that the participants had an interest in the study and desired to obtain results about the study to further their knowledge about stress and coping regarding their child with autism. Another benefit was to bring about new awareness of their coping styles and stress levels which they want to change or learn more about. Participants may have shifted their focus to another coping style they learned about or identified stress that could be alleviated through an available resource previously unknown. This study, when disseminated, may also identify needs to administrators, schools, organizations, and professionals who work with families who have children with autism.
CHAPTER FOUR

RESULTS

Data were obtained from 60 participants. The group of parents with children with autism consisted of 15 males and 15 females. A control group of parents of children without autism included 30 participants, 15 males and 15 females. The data were analyzed using SPSS. The analyses consisted of a Factorial MANOVA, post hoc ANOVAs, and frequency distributions. Anecdotal information from the interviews is indicated in the discussion section.

Demographics

Parents of children with autism

Results of the frequency distribution illustrate the demographics of the participants who had children with autism (See Table 4.1). There were 15 male participants and 15 female participants. The participants included fourteen married couples with children with autism. There were also two other individuals who were not married to each other who participated in the study, one was married and one wasn’t. The marital status of the participants revealed that all of the mothers were married, 97% of the fathers were married and only 3% were divorced. With the exception of one participant, all were either biological mothers or fathers to the child with autism. The exception was one female who was a step-mother. The participants’ ages ranged from 25-45 with 50% of the participants in the 31-35 age category, 23% in the 36-40 category, 17% in the 41-45 category and only 10% in the 25-30 category. Thirty-three percent of the
fathers had a high school degree, 33% had some college education, 14% had a bachelors degree and 20% had a graduate degree. Thirty-four percent of the mothers had a high school diploma, 34% percent had some college, 20% had a bachelors degree, and 6% percent of the mothers had a graduate degree. Ninety-four percent of the participants identified themselves as Caucasian. Six percent identified themselves as Hispanic.

Only three percent of the participants earned less than $20,000 per year. Thirty-three percent earned from $20,000-$40,000 per year, 23% earned a yearly income that ranged from $40,000 to $60,000, 18% earned from $60,000 - $80,000 per year and 23% earned over $80,000. Forty-three percent of the participants lived in a city/urban community followed by 30% who lived in a suburban community and 27% lived in a country/rural community. Twenty-three percent of the participants had one child, 37% had two children, 27% had three children, three percent had four and five children and seven percent of the participants had more than five children in their families.

Seven percent of the participants’ children with autism were two years of age, followed by 3% who were three, 17% who were four, 20% who were five, 23% who were six, 20% who were seven, and 10% who were eight. Consistent with current literature, 70% of the children with autism were male and 30% were female (Maurice, Green & Luce, 1996; Simpson & Zionts, 1992). Sixty percent of the identified children were the first born in their family followed by 30% who were the second child, 3% were the fourth child and 7% were the fifth child born in the family. Seventeen percent of the children with autism were around the age of 18 months when they were diagnosed with autism. Fifty-three percent were two years of age when diagnosed with autism and 30% were three years old.
Table 4.1

**Frequency Distribution for Parents of Children with Autism**

<table>
<thead>
<tr>
<th>Label</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
<td>50</td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
<td>50</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Married</td>
<td>29</td>
<td>97</td>
</tr>
<tr>
<td><strong>Participants Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-30</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>31-35</td>
<td>15</td>
<td>50</td>
</tr>
<tr>
<td>36-40</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>41-45</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td><strong>Relationship to Child</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological parent</td>
<td>29</td>
<td>97</td>
</tr>
<tr>
<td>Step parent</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td><strong>Mother's Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>5</td>
<td>34</td>
</tr>
<tr>
<td>Some college</td>
<td>5</td>
<td>34</td>
</tr>
<tr>
<td>Bachelors degree</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>Some graduate college</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td><strong>Father's Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>5</td>
<td>33</td>
</tr>
<tr>
<td>Some college</td>
<td>5</td>
<td>33</td>
</tr>
<tr>
<td>Bachelors degree</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
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<td></td>
</tr>
<tr>
<td>Hispanic</td>
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<td>6</td>
</tr>
<tr>
<td>Caucasian</td>
<td>28</td>
<td>94</td>
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</table>
### Family Income

<table>
<thead>
<tr>
<th>Income Range</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; $20,000</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>$20,000-40,000</td>
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<td>33</td>
</tr>
<tr>
<td>40,000-60,000</td>
<td>7</td>
<td>23</td>
</tr>
<tr>
<td>60,000-80,000</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>80,000</td>
<td>7</td>
<td>23</td>
</tr>
</tbody>
</table>

### Community

<table>
<thead>
<tr>
<th>Community Type</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban/City</td>
<td>13</td>
<td>43</td>
</tr>
<tr>
<td>Suburban</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Rural/Country</td>
<td>8</td>
<td>27</td>
</tr>
</tbody>
</table>

### Number of Children in Family

<table>
<thead>
<tr>
<th>Number of Children</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>7</td>
<td>23</td>
</tr>
<tr>
<td>Two</td>
<td>11</td>
<td>37</td>
</tr>
<tr>
<td>Three</td>
<td>8</td>
<td>27</td>
</tr>
<tr>
<td>Four</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Five</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Five</td>
<td>2</td>
<td>7</td>
</tr>
</tbody>
</table>

### Child's Age

<table>
<thead>
<tr>
<th>Age</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Three</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Four</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Five</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>Six</td>
<td>7</td>
<td>23</td>
</tr>
<tr>
<td>Seven</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>Eight</td>
<td>3</td>
<td>10</td>
</tr>
</tbody>
</table>

### Gender of Child with Autism

<table>
<thead>
<tr>
<th>Gender</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>21</td>
<td>70</td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
<td>30</td>
</tr>
</tbody>
</table>

### Birth Order of Child with Autism

<table>
<thead>
<tr>
<th>Birth Order</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>18</td>
<td>60</td>
</tr>
<tr>
<td>Second</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>Fourth</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Fifth</td>
<td>2</td>
<td>7</td>
</tr>
</tbody>
</table>

### Age of Child when Diagnosed

<table>
<thead>
<tr>
<th>Age at Diagnosis</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Around 18 months</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Two</td>
<td>16</td>
<td>53</td>
</tr>
<tr>
<td>Three</td>
<td>9</td>
<td>30</td>
</tr>
</tbody>
</table>
Control group

Table 4.2 is a frequency distribution of the demographics for parents who did not have children with autism. There were fifteen parent couples, married to each other, in the control group. The age ranges for the participants were from 25-48 with thirty percent between the age of 31-35, and thirty-seven percent between the ages of 36-40. All participants in the group were the biological parents to their typically developing child.

The mother's education ranged from high school graduate to a bachelors degree. Thirty-seven percent of the subjects had only a high school degree, three percent had some college, and ten percent had a bachelors degree. The father's education had more variability than the mother's with twenty-seven percent having only a high school degree, three percent having some college, ten percent having a bachelors degree, and ten percent having a graduate degree.

All thirty participants were Caucasian. Forty percent of the participants had an annual income between $20,000-40,000, forty percent between $40,000-60,000 and twenty percent had an annual income of $80,000 or more. Seven percent of the participants lived in an urban/city community, thirty-four percent lived in a suburban community, and sixty percent lived in a rural/country community. Of the thirty participants in the control group, fifty-four percent had two children, thirty-four percent had three children, and fourteen percent had four children.
Table 4.2

Parents who did not have Children with Autism

<table>
<thead>
<tr>
<th>Label</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
<td>50</td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
<td>50</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>30</td>
<td>100</td>
</tr>
<tr>
<td>Participants Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-30</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>31-35</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>36-40</td>
<td>11</td>
<td>37</td>
</tr>
<tr>
<td>41-48</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Relationship to Child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological parent</td>
<td>30</td>
<td>100</td>
</tr>
<tr>
<td>Mother's Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>11</td>
<td>37</td>
</tr>
<tr>
<td>Some college</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Bachelors degree</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Father's Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>8</td>
<td>27</td>
</tr>
<tr>
<td>Some college</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Bachelors degree</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>30</td>
<td>100</td>
</tr>
<tr>
<td>Family Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$20,000-40,000</td>
<td>12</td>
<td>40</td>
</tr>
<tr>
<td>40,000-60,000</td>
<td>12</td>
<td>40</td>
</tr>
<tr>
<td>80,000</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>Community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban/City</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Suburban</td>
<td>10</td>
<td>34</td>
</tr>
<tr>
<td>Rural/Country</td>
<td>18</td>
<td>60</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Number of Children in Family</th>
<th>16</th>
<th>54</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two</td>
<td>16</td>
<td>54</td>
</tr>
<tr>
<td>Three</td>
<td>10</td>
<td>34</td>
</tr>
<tr>
<td>Four</td>
<td>4</td>
<td>14</td>
</tr>
</tbody>
</table>
**Group comparisons**

Demographics for both groups were similar with the exception of the community which the participants lived in. Sixty percent of the participants who did not have a child with autism reported living in the country compared to twenty-seven percent of the participants with children with autism. Interesting, many parents with children with autism reported living in the city, however, the town they are referring to is less than fifteen thousand people. Results concerning community lived in may have been incorrect due to the perceptions of the participants.

**Statistical Analyses**

A 2x2 factorial design was used with two independent variables which were: group (parents with children with autism, parents without children with autism), and gender (male, female). There were eight dependent variables which included child related stress, parent related stress, life stress, task-oriented coping, emotion-oriented coping, avoidance-oriented coping, distraction-oriented coping, and social diversion coping. A 2X2 Factorial MANOVA was computed to evaluate the data. Eight post hoc ANOVAs were computed on each of the dependent variables to determine which ones were significant.

**Hypothesis One**

Hypothesis one states there will be a statistically significant interaction between gender and parent group on the each of the dependent variables. The results indicated a significant difference for group, $F(1,56)= 7.36, p<.000$. A significant difference was also found for gender, $F(1,56)=3.93, p<.001$. There was no statistical interaction between group and gender, $F(1,56)= .440, p<.891$ therefore hypothesis one was not supported.
Hypothesis Two

The second hypothesis states that parents who have children with autism will report different stress levels on the parent and child domain of the PSI than parents without children with autism. Table 4.3 represents the post hoc ANOVA for the parent domain portion of the PSI. Table 4.4 indicates the means and standard deviations between the PSI and groups. The relationship between parent group and parent related stress approached significance in this sample $F(1,56)=3.75, p<.058$, suggesting parents of children with autism ($M=121.30, SD=26.78$) had higher parental stress scores than parents without a child with autism ($M=110.06, SD=17.86$). Likewise, the relationship between gender and parent related stress approached significance in this sample, $F(1,56)=3.53, p<.065$, with females ($M=121.13, SD=23.77$) more likely to have higher parent related stress scores than males ($M = 110.23, SD= 21.79$) (Table 4.5).

Table 4.3
Post-Hoc Analysis of Variance

Dependent Variable: Parent Domain

<table>
<thead>
<tr>
<th>Source</th>
<th>Degree of Freedom</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>1</td>
<td>1892.81</td>
<td>1892.81</td>
<td>3.75</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>1782.15</td>
<td>1782.15</td>
<td>3.53</td>
</tr>
<tr>
<td>Error</td>
<td>56</td>
<td>28265.86</td>
<td>504.74</td>
<td></td>
</tr>
</tbody>
</table>
Table 4.4

Parenting Stress Index Means and Standard Deviations

Independent Variable: Groups

<table>
<thead>
<tr>
<th>Measures</th>
<th>Group 1</th>
<th>Group 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n=30)</td>
<td>(n=30)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Child Domain*</td>
<td>128.46</td>
<td>32.58</td>
</tr>
<tr>
<td>Parent Domain</td>
<td>121.30</td>
<td>26.78</td>
</tr>
<tr>
<td>Life Stress*</td>
<td>7.80</td>
<td>7.53</td>
</tr>
</tbody>
</table>

*p < .05

Table 4.5

Means and Standard Deviations for the Parenting Stress Index

Independent Variable: Gender

<table>
<thead>
<tr>
<th>Scale</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Child Domain</td>
<td>102.00</td>
<td>28.44</td>
</tr>
<tr>
<td>Parent Domain</td>
<td>110.2</td>
<td>21.79</td>
</tr>
<tr>
<td>Life Stress</td>
<td>5.60</td>
<td>6.39</td>
</tr>
</tbody>
</table>
Results indicated a statistically significant difference for child related stress on parent groups, $F(1,56) = 47.05, p < .000$. The results suggested that parents of children with autism ($M=128.46, SD=32.58$) had higher child related stress scores than parents without a child with autism ($M=86.16, SD=11.47$). Table 4.6 indicates the post hoc ANOVA for child domain.

The relationship between gender and child related stress scores approached significance in this sample, $F(1,56)=2.97, p < .09$, with females ($M=112.63, SD=35.36$) reporting more child related stress than males ($M=102.00, SD=28.44$). Hypothesis two was supported in part with parents of children with autism reporting significantly more child-oriented stress than parents without children with autism. However, parents of children with autism did not report significantly higher parent-oriented stress than parents who did not have a child with autism.

Table 4.6

Post-Hoc Analysis of Variance

<table>
<thead>
<tr>
<th>Source</th>
<th>Degree of Freedom</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>$F$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>1</td>
<td>26839.35</td>
<td>26839.35</td>
<td>47.05*</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>1696.01</td>
<td>1696.01</td>
<td>2.97</td>
</tr>
<tr>
<td>Error</td>
<td>56</td>
<td>31939.60</td>
<td>570.35</td>
<td></td>
</tr>
</tbody>
</table>

* $p < .05$
Life Stress

There was a statistically significant difference between the groups on life stress, \( F (1,56)=12.01, p<.001\), indicating parents who have a child with autism (M= 7.80, SD= 7.53) have more life stress than parents who do not have a child with autism (M=2.60, SD=3.01). No significant effect was found between gender and life stress (Table 4.7).

Table 4.7

Post-Hoc Analysis of Variance

<table>
<thead>
<tr>
<th>Source</th>
<th>Degree of Freedom</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
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<td>405.60</td>
<td>405.60</td>
<td>12.01*</td>
</tr>
<tr>
<td>Gender</td>
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<td>9.60</td>
<td>9.60</td>
<td>2.84</td>
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<tr>
<td>Error</td>
<td>56</td>
<td>1890.80</td>
<td>33.76</td>
<td></td>
</tr>
</tbody>
</table>

*p<.05
Hypotheses Three and Four

Hypothesis three stated that mothers and fathers of children with autism will report different coping strategies to manage their stress. Hypothesis four states that parents with children with autism will report different coping strategies than the comparative group.

Performance of participants on the five coping strategies of the CISS is reported by gender and groups in Tables 4.8 and 4.9. Scores for group 1 ranged from slightly below average to slightly above average according to the CISS norms. Scores from group 2 ranged from below average to slightly above average (Table 4.9).

Table 4.8

Means and Standard Deviations for the Coping Inventory for Stressful Situations

Independent Variable: Gender

<table>
<thead>
<tr>
<th>Scale</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Task*</td>
<td>64.03</td>
<td>7.45</td>
</tr>
<tr>
<td>Emotion*</td>
<td>32.33</td>
<td>8.02</td>
</tr>
<tr>
<td>Avoidance*</td>
<td>35.76</td>
<td>8.50</td>
</tr>
<tr>
<td>Distraction*</td>
<td>14.20</td>
<td>3.78</td>
</tr>
<tr>
<td>Social Diversion*</td>
<td>14.53</td>
<td>4.48</td>
</tr>
</tbody>
</table>

*p < .05

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Table 4.9

Coping Inventory for Stressful Situations Means and Standard Deviations

Independent Variable: Groups

<table>
<thead>
<tr>
<th>Measures</th>
<th>Group 1 (n=30)</th>
<th>Group 2 (n=30)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Task*</td>
<td>59.56</td>
<td>8.73</td>
</tr>
<tr>
<td>Emotion*</td>
<td>39.16</td>
<td>9.00</td>
</tr>
<tr>
<td>Avoidance</td>
<td>40.20</td>
<td>10.84</td>
</tr>
<tr>
<td>Distraction</td>
<td>16.56</td>
<td>5.11</td>
</tr>
<tr>
<td>Social Diversion</td>
<td>16.36</td>
<td>4.50</td>
</tr>
</tbody>
</table>

*p < .05

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Table 4.10 represents the post hoc ANOVA for task-oriented coping. Results indicated that there was a significant difference between the groups on task-oriented coping, \( F (1, 56)= 4.06, p< .049 \) indicating parents who do not have children with autism (M=63.26, SD= 5.95) use more task-oriented coping than those parents who have children with autism, (M=59.56, SD= 8.73). There was also a significant difference between males and females on task-oriented coping, \( F (1,56)= 8.13, p<.006 \) indicating males (M=64.03, SD=7.45) use more task coping than females (M=58.80, SD= 7.00).

Table 4.10

Post-Hoc Analysis of Variance

**Dependent Variable: Task**

<table>
<thead>
<tr>
<th>Source</th>
<th>Degree of Freedom</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>1</td>
<td>205.35</td>
<td>205.35</td>
<td>4.06*</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>410.81</td>
<td>410.81</td>
<td>8.13*</td>
</tr>
<tr>
<td>Error</td>
<td>56</td>
<td>2829.06</td>
<td>50.51</td>
<td></td>
</tr>
</tbody>
</table>

*p<.05*

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Table 4.11 indicates the post hoc ANOVA for emotion-oriented coping. The results revealed a significant difference between groups on emotion-oriented coping, $F(1,56) = 6.68, p < .012$, indicating that parents with children with autism ($M = 39.16, SD = 9.00$) engage in more emotion-oriented coping than parents without children with autism ($M = 33.16, SD = 10.26$). A significant difference was also found between gender and emotion-oriented coping, $F(1.56) = 10.91, p < .002$, indicating females ($M = 40.00, SD = 10.50$) engaged in emotion coping more than males ($M = 32.33, SD = 8.02$).

Table 4.11
Post-Hoc Analysis of Variance

<table>
<thead>
<tr>
<th>Source</th>
<th>Degree of Freedom</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>1</td>
<td>540.00</td>
<td>540.00</td>
<td>6.68*</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>881.66</td>
<td>881.86</td>
<td>10.91*</td>
</tr>
<tr>
<td>Error</td>
<td>56</td>
<td>4522.40</td>
<td>80.75</td>
<td></td>
</tr>
</tbody>
</table>

*p < .05
Table 4.12 indicates the post hoc ANOVA for avoidance-oriented coping. A significant difference was found between gender and avoidance-oriented coping, $F(1.56)=10.74$, $p<.002$ indicating that females ($M=43.30$, $SD=9.12$) use more avoidance coping than males ($M=35.76$, $SD=8.50$).

Table 4.12

**Post-Hoc Analysis of Variance**

**Dependent Variable: Avoidance**

<table>
<thead>
<tr>
<th>Source</th>
<th>Degree of</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>$F$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>1</td>
<td>26.66</td>
<td>26.66</td>
<td>.337</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>851.26</td>
<td>851.26</td>
<td>10.74*</td>
</tr>
<tr>
<td>Error</td>
<td>56</td>
<td>4436.40</td>
<td>79.22</td>
<td></td>
</tr>
</tbody>
</table>

*p<.05*
Table 4.13 indicates the post hoc ANOVA for distraction-oriented coping. The results revealed that there was a significant difference between gender and distraction-oriented coping, $F(1,56)=7.61$, $p<.008$, indicating that females ($M=17.23$, $SD=4.71$) engage in more distraction coping than males ($M=14.20$, $SD=3.78$).

Table 4.13
Post-Hoc Analysis of Variance

Dependent Variable: Distraction

<table>
<thead>
<tr>
<th>Source</th>
<th>Degree of Freedom</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>1</td>
<td>43.35</td>
<td>43.35</td>
<td>2.39</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>138.01</td>
<td>138.01</td>
<td>7.61*</td>
</tr>
<tr>
<td>Error</td>
<td>56</td>
<td>1015.46</td>
<td>18.13</td>
<td></td>
</tr>
</tbody>
</table>

*p<.05
Table 4.14 indicates the post hoc ANOVA for social diversion-oriented coping. Results also indicated a significant difference between gender and social diversion-oriented coping, $F(1.56) = 11.88$, $p < .001$, revealing that females ($M=18.16$, $SD= 3.51$) use social diversion as a coping strategy more than males ($M=14.53$, $SD= 4.48$).

Hypothesis three is supported in that mothers and fathers used different coping strategies to manage their stress. Results indicated a statistically significant difference between male and female on all coping scales. Hypothesis four was supported with results revealing that parents of children with autism reported different coping strategies than parents without children with autism.

Table 4.14

Post-Hoc Analysis of Variance

<table>
<thead>
<tr>
<th>Source</th>
<th>Degree of Freedom</th>
<th>Sum of Squares</th>
<th>Mean Square</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>1</td>
<td>1.667</td>
<td>1.667</td>
<td>.001</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>198.01</td>
<td>198.01</td>
<td>11.88*</td>
</tr>
<tr>
<td>Error</td>
<td>56</td>
<td>932.80</td>
<td>16.65</td>
<td></td>
</tr>
</tbody>
</table>

*p<.05
Interview Findings on Parent Reported Stress

Eighty-seven percent of parents reported the behavioral problems of their children with autism to be one of the most stressful issues. Eighty-seven percent of parents also reported the language barrier of the child with autism to be extremely stressful. The interview findings also revealed that sixty percent of parents reported the financial burden of therapy for the child with autism was stressful. Thirty-seven percent reported worrying about their other children and whether they get the attention they need because of the child with special needs. Thirteen percent of parents reported finding appropriate therapy for their child a stressful and frustrating experience. Other reported stress included the parents having problems with the school the child attended, finding a babysitter, and health concerns about their child with autism. Table 4.15 represents the stress parents reported about their child with autism during the interview. The list denotes a categorization of the actual responses elicited by the parents. Examples of behavioral problems included: screaming, biting, or hitting. If the parent listed their child as not talking or communicating, it was reported in the language barrier category. Examples of financial burden included the parents reporting not having enough money to pay for such things as therapy, doctor bills, or special technology needed for their child. Sibling concerns included parental worry about the lack of attention the sibling received compared to the child with autism, or that their typically-developing child might mimic the child with autism. The finding therapy category included not knowing what therapy to use, or where to take the child for appropriate intervention. School problems were categorized by parents reports that their child's teacher did not understand autism, or the parent was not sure if the child was making appropriate academic progress. Locating a baby-sitter was categorized by parents reporting that it was difficult to find a baby-sitter who could adequately care for their child with autism.
Health concerns were categorized by a parent stating that his/her child had other physical problems, such as increased ear infections.

Table 4.15

<table>
<thead>
<tr>
<th>Interview-Reported Stress</th>
<th>Frequency (n=30)</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Problems</td>
<td>26</td>
<td>87</td>
</tr>
<tr>
<td>Language Barrier</td>
<td>26</td>
<td>87</td>
</tr>
<tr>
<td>Financial Burden</td>
<td>18</td>
<td>60</td>
</tr>
<tr>
<td>Sibling Concerns</td>
<td>11</td>
<td>37</td>
</tr>
<tr>
<td>Finding Therapy</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>School Problems</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Locating a Babysitter</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Health Concerns</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>
Hypothesis Five

It was hypothesized that the most frequent resources used by parents of children with autism would be: support from spouse, support by friends, support group, and the agency where their child is receiving treatment. After a close review of the responses to the resources participants currently used in helping manage the stress associated with their child with autism, eighty-four percent of the participants listed their spouse as the most frequent resource for relieving stress. Results also indicated that the second most frequent resource used for relieving stress associated with raising their child with autism was their parents, followed by church and extended family. Resources such as friends, or health care providers were used less frequently (Table 4.16). The hypothesis was supported only in part with findings that the spouse was the most frequently used resource.
Table 4.16

Frequency Distribution For Most Frequently Used Resources by Parents of Children with Autism

<table>
<thead>
<tr>
<th>Primary Resource</th>
<th>Frequency (N=30)</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>25</td>
<td>84</td>
</tr>
<tr>
<td>Parents</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Therapist/Counselor</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Church</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>School</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary Resource</th>
<th>Frequency (N=30)</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents</td>
<td>15</td>
<td>50</td>
</tr>
<tr>
<td>Extended Family</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>School</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Church</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Parents as Teachers Program</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Support Group</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Friends</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Spouse</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Government Agency</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>
CHAPTER FIVE

DISCUSSION

The impact of having a child with disabilities is tremendous, especially when the disability is as handicapping as autism can be. According to Shorten (1996) parents should have support groups, other people to contact when needed, and enough information to answer questions about their child. Autism may be more difficult for parents to accept than other disabilities because children with autism can be non-affectionate and non communicative. A child with autism may act in a way that makes the parents feel their child is rejecting them. For some families, having a child with autism adds to the stress and magnifies existing problems, for others it creates a new set of problems (Siegel, 1996). It is often necessary for these families to obtain counseling or management skills for their family as well as their child. Classes are often offered in colleges and universities for behavior management and it would be helpful for professionals to help find resources for these families (Norton & Drew, 1994).

Conclusions

Although other studies have been conducted and found that parents who have a child with autism have more stress than parents without children with autism (Dewey, 1999; Kasari & Sigman, 1997; Sanders & Morgan, 1997), Guess (1998) found that there was no significant difference in stress when parents had a child with autism or not. Many studies have used the PSI for measuring stress, however, few studies were found relating to whether that stress was parent-
oriented or child-oriented. The current study broke the stress down into two
categories already used on the PSI; parent stress and child stress. Examples of
child-oriented stress are behavioral problems with the child, the child's overall
feelings toward the parents, how much the child laughs, plays or smiles, the
achievement levels of the child, and how adaptable the child is to certain
situations. Parent-oriented stress includes how confident an individual feels
about their parenting skills, if they receive support from their spouse, how
restricted they feel about being a parent, and what kind of feelings they have
toward their child.

It was hypothesized that parents who have a child with autism will report
different stress levels on the parent and child domain of the PSI than parents
without children with autism. This hypothesis was supported by results which
revealed that parents who have a child with autism reported more child-oriented
stress than those parents without children with autism. This is consistent with
Boyce and Behl (1991) who found that parents of children with a disability have
more child-oriented stress than parents without children with disabilities and also
consistent with Innocenti and Kwisun (1992) who found that parents who have a
child with a disability report more child-oriented stress than parents who do not
have a child with a disability. Innocenti and Kwisun (1992) also found that
parents who had three year olds with a disability reported significantly more
stress than the normative samples of three year olds. This data supported the
notion that parents with children who have a disability have higher stress directly
related to child factors (such as functioning level of the child) rather than parent
factors (such as resources and support).

The current results indicated that parents with children with autism had higher
parental stress scores than parents without a child with autism, however the
current study results were not statistically significant. This is also consistent with
Innocenti and Kwisun (1992) who found that parents who have a child with a disability reported higher parent domain scores than parents without children with disabilities, the findings were not significant. Reasons for this may be due to the small sample size.

A goal of the interview was to examine the reasons why parents feel stressed. Findings from the interviews suggest that parents who had a child with autism worry about their other children and whether they got the attention they needed because of the child with special needs. The interview findings also revealed that the financial burden of therapy for the child with autism, and the frustration of the language barrier of the child with autism is extremely stressful for parents. These reasons could lead to higher stress scores for families who have a child with autism than those who do not. Also noteworthy is the fact that the current study did not account for severity of autism, so parents who have a child with autism who is lower functioning may have rated more stress in their lives than those parents with higher functioning children with autism. Young and Roopnarine (1994) found that father's stress levels with their children with disabilities were equal to those stress levels found in fathers without children with disabilities. However, the authors felt the parents in their study who had children with disabilities did not fit the typical profile of persons who are overly stressed, as their children exhibited normal functioning within the family. They felt that the low stress levels might have been accounted for by the father's perception that their children were higher functioning than other children with disabilities.

The review of literature found no other studies which investigated the differences in how mothers and fathers cope with the stress associated with having a child with autism. For the current study, it was hypothesized that mothers and fathers would use different coping strategies to manage their stress. Results of the analyses revealed that across both groups, males used more task-
oriented coping than females such as analyzing the problem before reacting, adjusting priorities, coming up with solutions to the problems and scheduling time better. Although not a statistically significant finding, results also indicated that females had higher parent and child-oriented stress than males which may indicate that being more task-oriented could relieve some of the stress that the males experienced. Analyses also indicated that females engaged in emotion-oriented coping more than males such as focusing on the negative aspects of the problem, feeling anxious, becoming tense, and self blame. Females also had higher avoidance coping scores than males indicating that females engage in strategies such as taking walks, watching television, going shopping, and wanting to go to sleep. Females had higher scores than males on distraction-oriented coping indicating that they engage in more time away from the situation, buying things, eating, shopping, or sleeping. Finally, females had higher scores than males on social diversion coping indicating females were more likely to phone or visit a friend, ask advise from someone else, go to a party, or want to be around others when trying to cope with a stressful situation.

Although research has been conducted on coping strategies of parents who have a child with a disability, no studies were found regarding the coping strategies used specifically for coping with a child with autism with the exception of Guess (1998) who investigated coping strategies of parents with a child with autism, parents with a child with mental retardation, and parents of children without disabilities. Guess found that there were no differences between groups for emotion coping or problem focused coping as a way of alleviating their stressful situation. She believed that stress was a function of the parents inability to cope with their child with a disability, rather than the stress from the child’s condition. The current research study hypothesized that parents of children with autism will report different coping strategies than parents without
children with autism. Results from this study suggested that parents who do not have a child with autism use more task-oriented coping than parents who have a child with autism. This may explain the finding that parents of children with autism have higher stress levels than parents without children with autism. Examples of task-oriented coping are analyzing the problem before reacting, adjusting priorities, coming up with solutions to the problems and scheduling time better. Results also revealed that parents who have a child with autism engage in more emotion when coping with their stressful situation than parents who do not have a child with autism. Using emotion responses as a part of coping include behaviors such as focusing on the negative aspects of the problem, feeling anxious, becoming tense, and self blame. Results from the interviews confirm this finding in that parents often felt anxious about the financial burden and often blamed themselves for not knowing how to parent their child with autism. This finding is also consistent with parents of children with other disabilities. Cameron and Armstrong-Stassen (1991) found that mothers who felt less financially secure felt more stress in raising their child with a disability.

The interaction between gender and parent group on each of the dependent variables was also investigated. The expectation was there would be differences between female and male parents with children with autism. For example, one might hypothesize that males who have a child with autism use avoidance coping more often than females who have a child with autism. However, the MANOVA indicated that there were no statistically significant interactions between gender and parent group on any of the dependent variables, therefore the hypothesis was not supported.

Other research findings which are noteworthy were that females attributed more child related stress to their lives than did males, however this was not a statistically significant finding. Emotion-oriented coping are behaviors such as
focusing on the negative aspects of the problem, feeling anxious, becoming tense, and self blame. Although not significant, females were also more likely to have higher parent related stress scores than males (p<.065), indicating that females felt less competent in dealing with their child, and that they felt more isolated in their parental role than males do. Reasons for both of these findings may be the result of mothers spending more time with the child than fathers, especially in the current study where seventy four percent of the mothers did not work outside of the home.

The results of this study also revealed that parents with a child with autism have more overall life stress than parents without children with autism. This finding was statistically significant at the .001 level. According to the definition on the parenting stress index, life stress includes a recent divorce, marriage, pregnancy, moving to a new location, a financial decrease or increase, death of a family member, or legal problems.

Findings from the Interviews

When asked about the stress that is experienced from having a child with autism, 55% of the parents stated that the behavioral problems and language barrier were most stressful. These findings were also consistent with Sanders and Morgan (1997) who found that parents who had children with autism reported that a large portion of their stress was due to the behavioral problems such as self injurious behaviors, and inappropriate and loud verbalizations. Likewise, Randall and Parker (1999) found that parents of children with autism are faced with social and behavioral difficulties associated with having a child with a disability.

Thirty-five percent of the participants indicated that the financial burden of paying for therapy or services for their child was most stressful. These findings
are also consistent with Cameron and Armstrong-Stassen (1991) who found that financial problems were correlated to higher stress levels in parents of children with disabilities. The other ten percent of stress was accounted for by various things such as relations with siblings, wondering about the future of their child, problems with their child at school, and the short attention span the child has. After reviewing responses to the resources participants used in helping manage the stress associated with their child with autism, eighty-four percent of the participants listed their spouse as the most frequent resource for relieving stress. This is also consistent with research regarding parents who have a child with disabilities other than autism which revealed that parents utilize their spouse and family as resources when parenting their child with a disability (Hanline & Daley, 1992; Judge, 1998; Margalit & Ankonina, 1991). These results are also consistent with the study conducted by Margalit and Ankonina (1991) who found that greater family resources were components which predicted positive affect in parents who had a child with a disability. Results also indicated that the second most frequent resource used for relieving stress associated with raising their child with autism was their parents, followed by church and extended family. These results are also consistent with Shorten (1996) who found that parents of children with autism in a behavioral program used their church family as a resource for helping them with their child. In the current study, resources such as friends and health care providers were used less frequently.

All parents revealed that their child with autism was receiving treatment such as behavior modification, occupational therapy, play therapy or in special classes in their school. More than half of the parents indicated that their child only received intervention through the school system.

Findings from the interviews indicated that parents had a difficult time finding a babysitter to tend their children if they needed one. Parents indicated that it
was hard to find someone to care for their child due to the behaviors and lack of
communication the child exhibited. Only one participant felt that it was easy to
find a babysitter for their child.

Although many participants reported that they had not found any financial
resources to help with their child, many indicated they had not tried. Parents did
indicate that they were aware of government funding such as Medicaid, however,
for unknown reasons few of the parents reported having it.

Overall, parents of children with autism indicated that they used resources
such as their spouse, family, church, and friends. Many Parents reported that
they had their children involved in different therapies, behavior modification
and/or school. Most participants reported that they had no outside financial
resources.

Limitations

There are various limitations to the current study which should be noted. Most
notable is the limited number of participants in the study. Because of the low
number of participants, it is difficult to make steadfast generalizations to the
population as a whole. Another limitation is the lack of longitudinal information
collected. Participants were only administered testing instruments one time, so
any long term effects of stress and coping strategies could not be assessed.
Although difficult to assess, the severity of the children with autism was not
calculated into this study, therefore, parents may have answered questions
differently based on the intensity of their child's disability.

Although group 1 reported significantly higher stress than group 2 the control
groups scores played a factor in this. Specifically, the control group had lower
stress scores than normal compared to the PSI norms.

There were some participants who knew the researcher previous to the
study, therefore, information given may have been contaminated to some degree. Likewise, contamination could have occurred as one participant explained to the researcher that her husband “had help” filling out his questionnaire. As the researcher was not present during all the administrations of the instruments, it is difficult to assess how each one was filled out.

When analyzing the results of this study, it must be mentioned that external validity was questioned regarding the demographics of the participants. Only one participant was a step-parent, and 59 were biological parents to the children. Although it is unknown what the divorce rate is among parents who have children with autism, it would seem logical that it would be closer to the national divorce average which is estimated at fifty percent according to studies done at the University of Nebraska, Lincoln, (2001).

Implications

There are many implications for practitioners to utilize. First, parents who have a child with behavioral problems need to be taught strategies to minimize the difficulties and given resources for respite care. It is also evident that financial difficulties increase the stress load that a mother bears, therefore the financial security of the family need to be taken into consideration during intervention, and addressed when appropriate. Finally, since it is apparent from research that a mother who has a child with a disability can lower her stress level through the use of reframing, the practitioner should take time to assist her with this to help manage her stressful situation (Cameron & Armstrong-Stassen, 1991). Judge (1998) noted that professionals should encourage families to join a support group, or help them find resources and organizations for support. Haussler (1999) stressed the importance of collaboration with parents and professionals so the parents may handle their feelings better and have many
resources to utilize.

Hanline and Daley (1992) suggested that when there is a need for support services, families may be better served through the use of informal support rather than traditional service delivery models professionals often use. Hispanic families who have a child with a disability seem to have good coping resources. One reason for this may be the ability of families to utilize the resources they already have. In the current study there were no differences in reported resources between Caucasians and Hispanics, although there were only two Participants who were Hispanic. For the African American families, having a child with a disability did not significantly impact the pride of the family. One reason for this may be that this particular ethnic group has the ability to see positive aspects in meeting a challenge. Hanline and Daley stress that this culture has a very accepting attitude of others, regardless of ethnicity or disability. In the current study which consisted of primarily Caucasians, the parents of children with autism seem to prefer the informal support system including their spouse and family members. Outside resources such as physicians, agencies and support groups were used less frequently.

Although in the current study no parent indicated a need for more information about autism, these parents had already received the diagnosis of autism in their child, and may already have the information they needed. Hanline and Daley (1992) stated that the positive aspects of receiving outside support was not a significant finding in their study, however, it should not preclude professionals from referring families to outside resources nor does it suggest that these families could not benefit from more information. Most states have local support groups for parents of children with autism called Families for Effective Autism Treatment (FEAT). The goal of FEAT is for parents to meet one another, share concerns and get more information about autism and interventions. Other
resources include; The Autism Society of America, Council for Exceptional Children, American Association for Psychiatric Services for Children, National Association for Mental Health, and American Psychological Association. Available resources also include many books and journal articles. There are a few journals dedicated solely to autism and other developmental disorders including the Journal of Autism and Developmental Disorders. The Internet has a great wealth of information on autism with various resources around the United States.

Recommendations for Future Research

A recommendation for future research is to obtain more participants and to collect data over a period of time to assess the long term effects of the stress parents experience. It may also be advantageous to include the severity of autism as an independent variable to determine if parents vary in stress levels depending on the intensity of their child's disability. It may also be helpful in a future study for the researcher to be present during the administration of all data collection to increase internal validity.

It is also recommended that this study be replicated using random sampling for both groups to increase both external validity and reliability.
APPENDIX A

INFORMED CONSENT FORM
My name is Tammy Neil. I am a doctoral student at the University of Nevada, Las Vegas in the Special Education Department. I am inviting you to participate in a study I am conducting about stress levels and coping strategies of parents who have a child with autism. The purpose of the study is to assess parental stress levels and coping strategies and to identify resources which are used in managing the stress associated with parenting their child with autism. The method of my research consists of a short interview, and questionnaires on stress levels and coping strategies. The time spent with participants will be no longer than one hour. The study will be completed within the next four months. After the completion of the study, participants may obtain the results of the study by contacting me. My address and phone number are included on this form.

The possible benefits to parents may include learning about the stress associated with having a child with autism. The results may also help identify resources for those parents who are unaware of services. This study may benefit parents by identifying new ways of coping with the disability of their child. With these possible resources, parents may experience less stress in meeting the challenges of parenting their child with autism.

All names of participants will be strictly confidential and files will be kept in an undisclosed location. No person shall have access to those records for any reason. If you choose to become a participant in this study, it will be strictly voluntary and you may withdraw for any reason and at any time. If you do choose to participate, please sign the consent form below.

Name:________________________________________

Date:________________________________________
Listed below are the names and phone numbers of people to contact should you have any questions:

Tammy Neil  
P.O. Box 756  
Carthage, Missouri 64836  
417-358-8882  

University of Nevada, Las Vegas  
Department of Special Education  
Dr. Beatrice Babbitt  
4505 Maryland Parkway  
Las Vegas, Nevada 89154  
702-895-1106

University of Nevada, Las Vegas  
Office of Sponsored Programs  
702-895-1357

Sincerely,

Tammy L. Neil
APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE
Demographic Questionnaire

1. Subject number:_____________________ Gender: Male Female

2. Marital Status:
   Married
   Single
   Separated
   Widowed
   Divorced

3. Age:________________

4. Relationship to child with autism:
   Biological mother, biological father
   Step father, step mother
   Foster father, foster mother
   Adoptive father, adoptive mother
   Other (please specify):________________________

5. Occupation:__________________________

6: Education:
   High school
   Some college
   Bachelors degree
   Some graduate college
   Graduate degree
   Other:_________________________

7. Highest degree earned:____________________

8. Ethnicity:
   Asian
   African American
   Hispanic
   Native American
   Caucasian
   Other:_________________________
9. Average yearly income (combined income, if married)
   Less than $20,000
   $20,000 - $40,000
   $40,000 - $60,000
   $60,000 - $80,000
   Over $80,000

10. Community
    Urban/city
    Suburban
    Rural/country

11. Number of children in the family:
    a. One
    b. Two
    c. Three
    d. Four
    e. Five
    f. More than five

12. Ages of children in the family
    a. Child one _______ Female Male
    b. Child two _______ Female Male
    c. Child three _______ Female Male
    d. Child four _______ Female Male
Interview Questions

I. Thank you for agreeing to an interview. Today we are going to talk about the coping strategies and stress a parent goes through when they have a child with autism. Tell me a little about your child and his/her typical day.

II. Stress

1. Many parents find parenting a child with autism to be emotionally draining. What are some emotional stressors you experience?

III. Resources

From the list below, please number from one to five (e.g., 1 for the one you use most often and five for the one used least often) the resources you most frequently use to cope with the stress associated with your child with autism.

- Spouse
- Other parents who have a child with autism
- Parents
- Respite care provider
- Extended Family
- Agency where child receives intervention
- Friends
- Support group
- School
- Physician
- Church
- Psychologist or Counselor
- Govt Agency
- Other

1. Is your child currently receiving treatment or any intervention for his/her autism?
2. Do you use a babysitter? If so, is it difficult to find a caregiver for you?
3. Have you been able to locate any financial resources to assist you in meeting the needs of your child?
4. How long has your child had the diagnosis of autism?

IV. Do you have any questions about this study?

V. I will be combining your responses with those of other parents to analyze all the data. The results will be available to you after the study is completed.

VI. Thank you for your participation. If you have any questions or concerns you may call me at 417-358-8882, or Dr. Beatrice Babbitt in the
Answers to Interview Questions

I. Typical day of your child

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Stress

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

II. Resources
(see other page)

1. ________________________________________________________________

2. ________________________________________________________________

3. ________________________________________________________________

4. ________________________________________________________________

5. ________________________________________________________________

6. ________________________________________________________________

7. ________________________________________________________________

8. ________________________________________________________________

9. ________________________________________________________________

10. ________________________________________________________________

11. ________________________________________________________________

12. ________________________________________________________________
VII. Questions about this study
APPENDIX D

HUMAN SUBJECTS APPROVAL
DATE: August 17, 2001

TO: Tammy Neil

FROM: Dr. Fred Preston

UNLV Social/Behavioral Sciences Institutional Review Board

RE: Status on Research Project Entitled: "Coping Strategies and Stress Levels of Parents of Children with Autism"

OPRS Number: 30550701-61

Approval Date: August 16, 2001

This memorandum is official notification that the protocol for the project referenced above has been reviewed by the Office for the Protection of Research Subjects. The protocol has been determined as having met the criteria for exemption from full review by the UNLV Social/Behavioral Sciences Institutional Review Board. In compliance with this determination, the protocol has received approval through the expedited review procedure. The protocol is approved for a period of one year from the date of this notification and work on the project may proceed. The approval is effective August 16, 2001 and will continue for a period of one year.

Should the use of human subjects described in the referenced protocol continue beyond a year from the approval date, it will be necessary to request an extension.

If you have questions or require any assistance, please contact the Office for the Protection of Research Subjects at 895-2794.

cc: OPRS File
REFERENCES


Olson, D.H, McCubbin, H.I., Barnes, H., Larsen, A., Muxen, M., & Wilson, M.


