

2006

Family functioning and coping behaviors in parents of children with autism

Matthew J. Altieri

Follow this and additional works at: <http://commons.emich.edu/theses>



Part of the [Clinical Psychology Commons](#)

Recommended Citation

Altieri, Matthew J., "Family functioning and coping behaviors in parents of children with autism" (2006). *Master's Theses and Doctoral Dissertations*. 54.

<http://commons.emich.edu/theses/54>

This Open Access Thesis is brought to you for free and open access by the Master's Theses, and Doctoral Dissertations, and Graduate Capstone Projects at DigitalCommons@EMU. It has been accepted for inclusion in Master's Theses and Doctoral Dissertations by an authorized administrator of DigitalCommons@EMU. For more information, please contact lib-ir@emich.edu.

FAMILY FUNCTIONING AND COPING BEHAVIORS IN PARENTS OF
CHILDREN WITH AUTISM

by

Matthew J. Altieri

Thesis

Submitted to the Department of Psychology

Eastern Michigan University

in partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE

in

Clinical Psychology

Thesis Committee:

Dr. Silvia von Kluge (chair)

Dr. Nina A. Nabors

Dr. Carol Freedman-Doan

August 18, 2006

Ypsilanti, Michigan

ACKNOWLEDGEMENTS

I would like to thank all of the people who helped develop, organize, edit, and produce this thesis research, including my committee members, Silvia von Kluge, Nina Nabors, Carol Freedman-Doan; the Human Subjects Review Committee Chair, Karen Saules; and my friends and colleagues who edited, proofed, or simply provided support during the project.

Abstract

We looked at how a child with autism affects the dynamics and coping behaviors of a family. A majority of studies on families with a child with autism collect information from the mother but not the father. Therefore, this study examined the involvement of both parents from a family systems theory approach, which compares relationships among different familial variables, to determine the contributions of each individual to the developmental outcomes of the family unit. It was hypothesized that moderate levels of cohesion and adaptability would be associated with higher levels of positive coping mechanisms. Further, the more coping strategies implemented by a family would predict greater satisfaction with their family functioning. It was also expected that mothers would rate their families as more cohesive and adaptable, and more likely to implement positive coping strategies, and would perceive more social support than fathers. Results suggest that enmeshed families generally implement more positive coping strategies than other cohesion styles. Further, mothers perceive more social support from their family and friends than fathers do. It appears that families of children with autism have family styles similar to a normed group of families, except there were more chaotic and less rigid families in this sample. Future research ideas and possible implications of these findings are discussed.

Table of Contents

	Page
Acknowledgements	ii
Abstract	iii
Appendices	vi
List of Tables	vii
Introduction	1
Cohesion and Adaptability	3
Family Stress	6
Family's Conception of Autism	9
Coping Strategies	13
Social Support	14
Summary and Critique of Previous Research	17
Current Research	18
Method	20
Participants	20
Instruments	21
Family Adaptability and Cohesion Evaluation Scales-III	21
Family Crisis Oriented Personal Evaluation Scales	22
Perceived Social Support from Family and from Friends	23
Semi-Structured Interview	24
Procedures	24
Results	25

Scale Data	25
Hypotheses	30
Additional Findings	33
Qualitative Data	35
Discovery of Autism	35
Positive Learning Experiences	37
Discussion	39
Limitations and Conclusions	48
References	51

Appendices

1. Interview	
59	
B. Family Adaptability and Cohesion Evaluation Scales-III	
60	
C. Family Crisis Oriented Personal Evaluation Scales.....	62
D. Perceived Social Support-Family	65
E. Perceived Social Support-Friends	66
F. Informed Consent	67

List of Tables

Table 1. Scale Data	25
Table 2. Subscale Data	26
Table 3. Sample Frequencies for Levels of Cohesion	26
Table 4. Sample Frequencies for Levels of Adaptability	27
Table 5. Comparison of Cohesion Levels between Sampled Families and Normed Families	28
Table 6. Comparison of Adaptability Levels between Sampled Families and Normed Families.	29
Table 7. Comparison of Family System Levels between Sampled Families and Normed Families	29
Table 8. Perceived Social Support and Cohesion	31
Table 9. Perceived Social Support and Adaptability	32
Table 10. Levels of Cohesion and Family Coping Mechanisms	35
Table 11. Possible Causes of Autism According to Parents	37

Introduction

The key to optimal childhood development lies in the influences of the immediate environment. The family system, as part of the environment, plays a central role in the child's developmental outcome (Sameroff, 1990). In studies of families with autism, researchers have traditionally examined this interaction by focusing on the parents' effect on the child, not the child's effect on the parents (e.g., Kanner, 1943). More recently, studies have focused on the difficulties that both parents face because of the effects of caring for a child with autism and the strategies that are employed to cope with the stress (e.g., Gray, 2002; Schall, 2000). Seligman and Darling's (1997) book, *Ordinary Families, Special Children*, is one example illustrating the growth of the literature base that focuses on how children with disabilities affect the other members of the family system. The childhood disorder of autism is the center of a number of these studies.

The majority of autism studies focus on the mother-child relationship and exclude any analysis of the father and siblings (e.g., Hornby, 1994), or assess the siblings but not the father (e.g., Rivers & Stoneman, 2003), or include either the mother or the father from each family but not both (e.g., Gray, 2002). The contributions of the father in a family with a child with autism are important but are difficult to assess. Mothers have useful insights about the effects on the other family members, but each member of the family has a different point of view that the mother may not completely understand. Clinicians and other mental health providers who work with families of a child with autism will benefit from exploration of the father's contributions to the family system. In addition, the effect a child with autism has on the father when compared to the effect on the mother may provide psychologists with some insight into the family structure (Morgan, 1988).

This research compares the contribution from both parents in the areas of family functioning (cohesion and adaptability) and coping strategies.

Family systems theory has gained popularity in the last several decades as a tool for analyzing family functioning. In addition to examining dyads within the family (e.g., mother-child relationship or sibling relationship), family systems researchers and clinicians assess the views and actions of the entire family (Seligman & Darling, 1997). Other systems that interact with the family include friends, extended family members, society, school, and other service agencies (Morgan, 1988). Minuchin (1974) provides an explanation of this approach to family assessment: “The individual can be approached as a subsystem, or part of the system, but the whole must be taken into account” (p. 27). Each family member, therefore, is a crucial part of the entire system. If a significant event happens to one family member, it affects the entire family. Thus, the functioning of the family unit is altered when one member of the family receives the diagnosis of a chronic disability (Seligman & Darling, 1997).

In most cases, a child with autism has low social functioning, impairment in communication, and aggressive and self-destructive behaviors. Studies report the prevalence of autism to be anywhere from about 5 cases in every 10,000 individuals (American Psychiatric Association, 2000) to 60 cases in every 10,000 children 18 years old or younger (Fombonne, 2003). Morgan (1988) considered autism to be the most severe childhood behavioral disorder with the most complex developmental pattern. A child with autism is a large stressor on the family because of the ambiguity of diagnosis, the severity and duration of the disorder, and problems with the child’s lack of adherence to social norms (Bristol, 1984). The stress increases when parents realize that there is no

cure for autism (Liwag, 1989). A family with a child with autism may need to make adjustments in order to cope and function at an adequate level. The purpose of this study was to measure family functioning and coping strategies and to determine how these constructs are related in families with children with autism. The literature reviewed below highlights different aspects of family functioning and coping strategies that may be relevant in families with a child with autism including cohesion, adaptability, conception of the disorder, and social support.

Cohesion and Adaptability

A well-functioning family has a good balance of cohesion and adaptability (e.g., Olson, Portner, & Lavee, 1985; Seligman & Darling, 1997). “Family cohesion is defined as: the emotional bonding that family members have toward one another” (Olson, Portner, & Lavee, 1985, p. 4). Minuchin (1974) suggests that the extremes on the continuum of cohesion in families are the concepts of enmeshment and disengagement. Highly enmeshed families are overly involved in and protective of their children’s lives. Such overly protective families can have detrimental effects on the development of a child with autism because they may not promote the growth and independence of the child. On the opposite end of the continuum, disengaged families have rigid boundaries between family roles (e.g., parent-child and husband-wife). It is likely that these families are underinvolved because involvement causes anxiety (Minuchin, 1974). The child with the disability in this type of family would be free to develop independence but may not feel loved and protected. Seligman and Darling (1997) showed that families with a child with a disability that function at an optimal level have a coping style between enmeshment and disengagement. For a well-functioning family with a child with autism,

Bristol (1984) found that families who are close-knit, able to express emotions, supportive, and involved in outside recreational activities (a combination of characteristics that are between extreme enmeshment and disengagement) are better able to adapt to the stresses of caring for a child with autism.

Adaptability is a measure of the family's ability to change in response to a stressful situation (Olson, Russell, & Sprenkle, 1980). On one end of the adaptability continuum is the rigid family that does not change anything within the system in response to a large stressor. Typically, this type of family holds to the rigid belief that the father is the head of the household, which would mean he would not assist with chores or childcare (women's work), possibly placing a large burden on the mother. This scenario may result in the mother having little time for herself or the other children in the family. The rigid family may have a difficult time caring for a disabled child who requires additional care because the other members of the family are unwilling to lessen the mother's increased burden (Olson, Russell, & Sprenkle, 1980).

On the other end of the continuum are chaotic families who are characterized by unstable and inconsistent change. In chaotic families, the small number of rules may be constantly changing. There may be no family leader and there may be frequent role changes. Chaotic families can quickly vacillate between the cohesion concepts of enmeshment and disengagement (Turnbull & Turnbull, 1986). McCubbin and McCubbin (1988) reported that on the family adaptability continuum, flexible and laissez-faire families are in between the rigid and the chaotic families. The flexible family system is high on predictability and high on adaptability. The laissez-faire family system includes moderate predictability and low adaptability. In laissez-faire families, inertia and

indecision can take the place of organization and action. The flexible family system appears to be the most effective organization when caring for a child with a disability (McCubbin & McCubbin, 1988). Singer and Powers (1993) found that well-functioning families are flexible, open to change, and resilient.

Not only can a well-functioning family decrease the overall stress on the family system, it can improve the status of a child with a disability. The family environment is important to the child's welfare and development (Sameroff, 1990). Although the early biological status of a child may be integral to the development of autism, the environmental conditions may affect the outcome of a child with autism. For example, Wilson (1985) found that the social conditions surrounding the child were better predictors of the child's outcome than their early biological status (measured by birth and pregnancy conditions). In addition, family variables that foster development can improve the condition of a child with mental retardation (Sameroff, 1990). Werner and Smith (1982) conducted a longitudinal study of children on the Hawaiian island of Kauai who were at high clinical risk due to a severe early trauma at two years of age. The resilient group of children who did not develop any problems by the age of eighteen were compared to the children who developed a problem by eighteen. The protective factors of the children who did not develop a problem included favorable parental attitudes, low levels of family conflict, counseling and remedial assistance, small family size, and a lower amount of stressful life experiences. This indicates that the family environment was important to the development of these children.

The multiple pressures in the family environment include the amount of stress from the environment, the family's resources for coping with that stress, and the parents'

flexibility in understanding and dealing with their child. These pressures play an important role in fostering or hindering a child's intellectual and social competencies. In addition, the experience of the developing child is partially determined by the beliefs, values, and personality of the parents, partially by the family's interaction patterns, and partially by society (Sameroff, 1990). Sameroff describes the cyclical nature of a child's development within the family system. "Changes in child behavior are related to antecedent parental activity, and there is clear evidence that changes in parental activity are related to antecedent child behavior" (p. 108). In other words, the family environment affects the child's development and the child's behavior affects other people in the family environment.

Family Stress

There is conflicting evidence on whether parents of children with autism endure more stress than parents of children without autism. Koegel, Schreibman, O'Neill, and Burke (1983) found that parents of children with autism did not differ significantly on measures of stress when compared to a normative group of happily married couples. However, McKinney and Peterson (1987) discovered that parents who have a child with autism endure more stress than parents of children without autism. Further, Sivberg (2002) compared level of stress and types of coping strategies of autistic and non-autistic families. This study showed that families with a child with autism have a higher level of stress and different coping behaviors than families without a child with autism. Families with a child with autism employed more avoidance coping behaviors (e.g., distancing oneself from the rest of the family), whereas families without a child with autism scored higher on self-control, social support, and problem-solving coping mechanisms (Sivberg,

2002). In addition, Sharpley, Bitsika, and Efremidis (1997) found that parents of a child with autism reported higher levels of anxiety and depression than the normal population. Perhaps the reason that the Koegel et al. (1983) study discovered no difference in stress levels between the two types of families that they included only parents of young children with autism who were receiving special services, whereas the other studies included a diverse age group of children with autism who were not receiving the same extraordinary services. It seems that the stressors of raising a child with autism that accumulate over time and the absence of adequate resources and support lead to depression and burnout (Morgan, 1988).

There are a few published reports of interviews with parents who have a child with autism (e.g., Gray, 2002; Schall, 2000). The parents describe many hardships and stressors encountered while raising a child with autism. Caring for a child with autism can be a twenty-four hour, seven day a week job throughout the child's entire lifetime. DeMyer (1979) found that parents of children with autism are at a high risk for marital discord. More than half of the families in DeMyer's (1979) study had a weak affectional bond between the parents. Some mothers report serious limitations on their careers due to their child's disability. For the mothers who wanted to work outside the home, few were able to seek outside employment due to the high level of care that must be provided for a child with autism (Gray, 2002). The combination of difficult emotional and physical behaviors displayed by the child with autism creates a high level of stress on the entire family.

The increased level of stress can take its toll on families with a child with a chronic disability. Crnic, Friedrich, and Greenberg (1983) completed a literature review

of studies that assessed parental attitudes, personality, emotional difficulties, marital satisfaction and psychosocial problems related to raising a child with mental retardation. This study suggested that such families are at greater risk for numerous difficulties (e.g., marital, emotional, and physical problems) than families with nonretarded children. Studies of parents of children with autism report greater levels of stress and depression, and lower levels of marital intimacy than do parents of normally developing children (Fisman, Wolf, & Noh, 1989). Mothers of children with chronic disabilities are more at risk for psychological disorders such as anxiety and depression. There is evidence that the very nature of autism causes this condition to be more stressful for families than other childhood disabilities (Dumas, Wolf, Fisman, & Culligan, 1991). In the Dumas et al. study, most of the mothers of children with autism described themselves as under more stress and experiencing more depression than did mothers of normal children or children with Down syndrome. In addition, the fathers of children with autism reported higher levels of stress than did parents of normal children or children with Down syndrome. The fathers of children with autism in this study did not report significant levels of depression. Several studies have found that mothers of children with autism suffer from higher levels of anxiety and depression than do fathers of children with autism (e.g., Beckman, 1991; Gray & Holden, 1992; Moes, Koegel, Schreibman, & Loos, 1992; Sharpley, Bitsika, & Efremidis, 1997). However, fathers of children with disabilities, in comparison to mothers, have higher levels of stress associated with the child's communication abilities (Frey, Greenberg, & Fewell, 1989) and in their feelings of attachment to the child (Beckman, 1991; Krauss, 1993). In DeMyer's (1979) study, one hundred percent of mothers of children with autism reported some symptoms of physical

and psychological tension. DeMyer believes that fathers seem to have some of the same troubles as mothers, but they are unable to express it. Most of the fathers in the study expressed concern about the well-being of their wives due to the excessive burden (DeMyer, 1979). The higher level of burden on the mother may explain the increased marital distress among families of children with disabilities (Patterson, 1991). If the mother takes on the majority of the caregiving duties related to the child with autism, then the other children may receive less attention. In addition, the mother may have little time for herself or her husband because of the increased amount of caregiving time that a child with autism requires. The family may struggle to achieve a balance within the disrupted system and to acquire effective coping strategies.

Family's Conception of Autism

The balance of the family system can be restored by acquiring new resources (e.g., social support), learning new coping behaviors, and/or changing the way the situation is viewed (Patterson, 1988). Seligman and Darling (1997) expand on Patterson's suggestion: "The degree to which the family is in trouble may depend on how it conceptualizes or reframes its life circumstance, how supportive family members are of each other, and how much social support is available outside of the family" (p. 9).

Typically, the disruption of the family system begins with the recognition of autism in a child. The ABCX family crisis model (McCubbin & McCubbin, 1987) is an explanation of the events following a significant change in the family. This model can describe the stress that assails the family after the recognition of autism in a child. "A" stands for the stressor event (child with autism), "B" is the family's crisis-meeting resources, "C" is the way the family defines the event, and "X" is the crisis (McCubbin & McCubbin, 1987).

The “A” factor is a significant transition in the family’s life that can produce a change in the family system. The family may need to activate its existing resources to prevent the stressor from becoming a crisis. The “B” factor relates to the family’s flexibility and quality of relationships prior to the presence of the child with autism. One way in which the family can acquire more resources is by utilizing community services. The “C” factor is the way the family defines the event of having a child with autism. This factor is a product of the family’s values and its previous experience in dealing with crises. These previous values and experiences may change after the child is diagnosed with autism. Ellis (1987) explains that it is not the event that is disturbing; it is the meaning attributed to the event that may cause distorted thinking. Functioning on all three factors together represents the family’s ability to cope and perhaps to prevent the stressor from creating a crisis (“X” factor). If a crisis does arise, the family may be unable to restore balance and stability in the system. Thus, the stress may never become a crisis if the family is able to draw upon adequate resources and if they perceive the situation as manageable (Seligman & Darling, 1997).

After their child is diagnosed with autism, the parents may need to consider their attitude about the event. The parents recognize that the child may never go to college, get married, or lead a “normal” life. “Family members may see little relief when they look to their future. Instead of independence, growth, self-fulfillment, and differentiation, a family may see only despair, dependence, and social isolation” (Seligman & Darling, 1997, p. 11). In addition to considering their attitude towards having a child with autism, the parents may need to confront their previous beliefs concerning individuals with disabilities. For example, the parents may have disliked and/or simply ignored

individuals with a disability before realizing that their child has a disability. When the family confronts their attitude towards the event, it may also lead them to confront their previous beliefs about disabilities. The parents may reverse their previous attitude of disdain into becoming advocates for better services for children with autism (Marshak & Seligman, 1993). The family must come to terms with the changes that occur when raising a child with autism or they may never cope well with this situation.

The family's conception of the cause of autism may be a part of the psychosocial adaptation to the disorder. "Parents do develop explanatory models of autism that succeed in making sense of it for them, and which help them cope with it" (Gray, 1995, p. 116). Kanner (1943) published the first major study about autism in which he described his controversial belief about the etiology of autism. Many people attribute the origin of the belief that autism is caused by parental psychopathology to Kanner. In Kanner's (1992; originally published in 1971) follow-up study, he explained that he only made observations of the families and did not create any inferences concerning the etiology of autism. Although Kanner (1943) explained that none of the parents in the study were "warmhearted," he assumes that children with autism are born with the "innate *inability* to form the usual, biologically provided affective contact with people" (p. 250, italics added). It seems that Kanner favored a causal explanation that included nature and nurture (DeMyer, 1979). Unfortunately, many people have ignored Kanner's inclusion of a biological basis for autism and have focused on his statements about cold, distant, and intelligent parents of children with autism. The scientific community refuted this parental cause of autism a few decades ago (for a review of the literature see Mackowiak, 2000), but this belief persists in the community. There are a few parents

who adhere to Kanner's explanation and indicate that their own behavior is the cause of their child's autism. These parents believe they are being punished for wrongs they committed before the birth of their child (e.g., Furnham & Buck, 2003; Gray, 1995). Mothers are more likely to believe that they are to blame for their child's autism than fathers are (Gray, 1995).

Kleinman's (1980) explanatory model of illness indicates that lay explanations of an illness often vary greatly from scientific explanations. This is the case even when the lay people are well-educated and have frequent contact with health care workers. Currently, the scientific community believes that autism has a biological basis, but the specific cause has not been discovered. Many scientists believe that several factors combine in the etiology of autism (Gray, 1995). A person's conceptualization of a disorder can lead to the acceptance or rejection of various treatments. Gray (1995) interviewed parents of children with autism to determine what they believed caused the disorder. The most common explanation for the etiology of autism was a trauma related to a difficult birth. Congenital damage and genetics were also found to be common explanations for the cause of autism. Some of the respondents stated that odd behavior in other family members was evidence that autism is inherited through genes. Furnham and Buck (2003) found that most parents of children with autism accepted a genetic cause or congenital damage (e.g., brain damage, complications during pregnancy) as an explanation for the etiology of their child's autism. Parents in Furnham and Buck's study were less likely to accept psychogenic theories because these theories lay blame on the parents themselves. Educational, behavioral, and dietary interventions were deemed as the most popular and most effective treatments by the parents in this study. Regardless of

the parents' beliefs concerning the etiology and treatment of autism, they were aware that there is no cure for autism and the success of interventions varies from child to child.

Although the parents of children with autism were more knowledgeable about the disorder than other lay people were, lay people's beliefs about the etiology and treatment of autism are similar to the current academic beliefs (Furnham & Buck, 2003).

Currently, there are no studies on autism that directly compare the parents' belief about etiology with how it affects their child's developmental outcome.

Coping Strategies

The family may search for other effective methods of coping to reestablish the balance within the family system. Gray (2002) found that the most popular coping strategy was support from family members. Other positive coping strategies included participation in religious and other individual activities. A popular negative coping mechanism was the family's withdrawal from other family members, friends, and society. Bristol (1984) found that families with a child with autism were more likely to emphasize strong moral and/or religious standards for coping than were families without a child with autism. In addition, families of children with autism were less likely to engage in social and recreational activities. McCubbin and Patterson (1981) describe some internal and external coping strategies. Internal coping strategies are when an individual changes one's view of the situation. Family members can adhere to the belief that the problems will resolve themselves over time. This is not a good coping strategy in families of a child with autism. Although the child's functioning can improve over time, the child will always display some symptoms. One internal coping mechanism studied in Gill and Harris' (1991) research is commitment to a set of values. This includes one's sense of

purposefulness and one's adherence to a set of philosophical and/or religious values.

They found that mothers of children with autism who were highly committed to a set of values had fewer symptoms of depression than did mothers who were not committed to a set of values.

The external coping strategies developed in McCubbin and Patterson's (1981) research included social support, spiritual support, and formal support (community resources such as doctors and teachers). The most often studied external coping strategy is social support. These external coping mechanisms may be the most important for families of a child with autism, but unfortunately it can be difficult to find quality support networks.

Social Support

Most families begin by seeking formal social support to aid in caring for the child with autism. These families enlist the support of medical doctors, respite care, psychologists, social workers, and special education teachers. After acquiring formal social support to fulfill the physical and psychological needs of the child, the family typically seeks informal social support such as family members outside of the home, friends, and support groups. Families with a child with autism often require outside help to combat the stress. Konstantareas and Homatidis (1989) found that the stress level of mothers of children with autism was negatively related to perceived level of social support. In addition, Frey, Greenberg, and Fewell (1989) found that mothers of children with disabilities who had more helpful social support networks had better family adjustment, whereas the fathers in the study who felt more criticism from their social support networks had poorer family adjustment. As reported earlier, Sivberg (2002)

found that parents with a child with autism had lower scores on social support measures than did parents without a child with autism. Sivberg hypothesized that these lower scores reflected a gradual deterioration of social support over the years due to stress on the family system.

General social support is of great value to parents of children with autism, but Sharpley, Bitsika, and Efremidis (1997) found that family members who provide assistance and have an understanding of the child's difficulties are the most valuable support. Families with a child with autism may gradually lose touch with their friends because of the reduced amount of time that they are available and also because the friends may feel they are unable to help or understand the burden of raising a child with autism. Parents report that it is important to find friends who accept their child's disability and help them lead a normal social life (Gray, 2002). In Gray's (1994) study, families reported that they believe it is difficult for society to accept a child with autism, and that there is social stigma and embarrassment associated with the inappropriate public behavior that these children might display. Some parents choose to isolate themselves instead of facing the frustration of taking their child out in public (DeMyer, 1979). Extended family members may reject the child with autism or distance themselves from the family. The parents of a child with autism often describe relatives as cold, distant, and generally unhelpful (Schall, 2000). The combination of the rejection from family members and the stigma felt from members of the community increases the burden of families of a child with autism. However, some parents report that they find friends who accept their child's autism and help them to lead normal social lives (Gray, 2002). An adequate social support network can assist the family with a child with autism

to cope with the constant stress. Mothers of children with autism who perceive social support to be accessible report fewer stress-related somatic problems and depressive symptoms than do mothers with less perceived social support (Gill & Harris, 1991; Gray & Holden, 1992). Dunn, Burbine, Bowers, and Tantleff-Dunn (2001) found that the failure to receive and seek social support corresponded with increased levels of spousal problems. Thus, this coping mechanism is another strategy that allows families with a child with autism to function appropriately.

Social support has been shown to buffer the effects of marital stress (e.g., Rivers & Stoneman, 2003), but spousal support for mothers has the most positive effect on the coping of the family (Seligman & Darling, 1997). Unfortunately, fathers of children with disabilities can employ negative coping behaviors. Houser and Seligman (1991) found that fathers of children who are mentally retarded use more withdrawal and avoidance coping behaviors than do fathers of children who are not mentally retarded. They suggested that if the father participates in avoidance and withdrawal behaviors, then it is likely that he is not helping his family care for the child with the disability. It may be helpful if each family member takes on more of the caregiving and household duties because of the extra difficulties that arise when caring for a child with autism. If the other siblings help with the caregiving duties, the father assists the mother more often, and he is psychologically supportive of the mother, then the stress level of the entire family may decrease (Houser & Seligman, 1991). The family may need to adapt, negotiate, and communicate in order to handle the constantly changing environment.

Krauss (1993) conducted a study with similar factors to the current proposed research, but he did not focus on autism. He found that mothers and fathers of children

with disabilities differ significantly in their ratings of the family's adaptability and cohesion. The mothers rated the families as more adaptable and cohesive as compared to fathers. There were no significant differences between mothers and fathers on measures of social support. For mothers and fathers, greater parenting stress was associated with poorer family functioning (lower levels of adaptability and cohesion). Despite this, mothers seemed to be less affected than the fathers were by aspects of family functioning. Krauss proposed that this is due to the idea that mothers are considered creators of the family environment.

Summary and Critique of Previous Research

There has been little family systems research conducted with families of children with autism. Most of the studies combine autism with other childhood disorders into the chronic disabilities category (e.g., Frey, Greenberg, & Fewell, 1989). The studies that compare the stress of a family with a child with autism to families of children with other disorders (e.g., Down syndrome) indicate that the families of children with autism experience more stress, depression, and anxiety (e.g., Dumas et al., 1991). It may be beneficial for researchers and clinicians to see the effects that a child with this unique developmental disorder has on the family system. Based on the model proposed by Olson et al. (1985), one would expect that families who report moderate levels of cohesion and adaptability would be better functioning than families who report "extreme" levels of these two variables. However, they reported that families who report "extreme" levels of cohesion and adaptability and are satisfied with their family's functioning will function "well."

Many of the studies on the effect a child with autism has on the family gather information from the mother but not the father (e.g., Rivers & Stoneman, 2003). There are studies on families of children with autism that include an assessment of both parents (e.g., DeMyer, 1979), but the field may benefit from an update on the status of this type of family considering the increase in services and the reported increase in the prevalence of autism (Fombonne, 2003). There are a few areas that can improve the functioning in families of children with autism. These areas are cohesion and adaptability (e.g., Seligman & Darling, 1997), coping mechanisms such as social support (e.g., Gray and Holden, 1992), and the conceptualization of the disorder (e.g., Gray, 1995). There are many studies that measure the coping mechanisms employed by families of children with autism, but none of the studies include a measure of family functioning and satisfaction with the family's functioning. Finally, many of the studies on families of children with autism contact the participants through the mail for data collection, which is a time efficient but impersonal and potentially confounded (sample bias) method. The current study implemented face-to-face interviewing techniques that provided the experimenter with knowledge that questionnaires cannot provide (e.g., Schall, 2000).

Current Research

The current study measured coping mechanisms (focusing on perceived social support), family functioning (cohesion and adaptability), satisfaction with the family's level of functioning in families with a child with autism, and parents' beliefs about the etiology of autism. In addition, both the mothers' and the fathers' self-report of family functioning and coping strategies was collected and compared. Information from the mother and the father is rarely included in studies of children with autism. The families were asked a

series of qualitative questions (see Appendix A). The purpose of this study was to build a model of how these variables relate to each other and to predict coping levels in families of a child with autism. This study is unique because there are no known studies of families of children with autism that measure the family's satisfaction with its functioning and few studies that measure cohesion and adaptability in these families. In addition, most studies of this format do not include input from both parents. Finally, most studies of families of children with autism elicit information through mail, whereas this study conducted face-to-face interviews at the family's home. The current study expected to find similarities with Krauss' (1993) findings, but the inclusion of only the autistic spectrum disorders revealed some interesting differences. In this study, the following hypotheses and research questions were examined:

- Moderate levels of family cohesion and adaptability would be significantly related to higher levels of perceived social support. We believed that the positive family functioning (Olson et al., 1985) would be related to a positive coping behavior (e.g., Frey et al., 1989) for these families.
- The more coping strategies the family used, the more likely they were satisfied with the functioning of their family. The justification for this hypothesis is similar to that in the previous hypothesis. We expected that these two positive features would be significantly related.
- Mothers would have higher ratings of the family's coping mechanisms than fathers would (based on the F-COPES). It appears that positive coping behaviors are important to mothers of children with autism (e.g., Gill & Harris, 1991), where fathers of

children with disabilities are more likely to implement negative coping mechanisms such as avoidance (e.g., Houser and Seligman, 1991).

- Mothers would be more likely to rate their family as cohesive and adaptable and be more satisfied with the functioning of the family than fathers would. This hypothesis is based on Krauss' (1993) similar findings.

- Mothers would perceive that they have more social support than fathers would. Although Krauss (1993) did not find a significant difference between mothers and fathers on this variable, we believed that this significant difference would be present because of the importance of social support as a coping behavior for mothers (e.g., Gill & Harris, 1991).

Method

Participants

The experimenter interviewed 26 pairs of parents with a total number of 52 participants (26 mothers, 26 fathers). The parents were recruited from local autism organizations in southeast Michigan and at an “Autism in Michigan,” Yahoo E-mail group. The families were primarily European-American except for 2 multiracial families and an Arab-American family. The average number of siblings was 1.1, with a range of 0 to 3. The age range for the children with autism was 3 to 16 years old with a mean of 7.5. There were 23 boys and 3 girls in this sample (88.5% male), which is similar to the 5:1 male to female ratio of children with autism (e.g., Fombonne, 2003). The average age that the child was diagnosed with autism was 3.0, with a range of 1 to 6. Only families with the following characteristics were included in data analyses. The children met criteria in the Diagnostic and Statistical Manual of Mental Disorders (4th ed., text

revision) for autism, Asperger's disorder, or Pervasive Developmental Disorder, Not Otherwise Specified (atypical autism) (American Psychiatric Association, 2000). The children spent the majority of the week (40 hours or more) at home under the care of one or both of the parents. The families had two biological parents living in the home, and both parents participated in the research.

Instruments

Family Adaptability and Cohesion Evaluation Scales-III (FACES-III; Olson et al., 1985) (see Appendix B).

The FACES-III is a 40-item self-report questionnaire that measures a family member's perceived and desired family cohesiveness and ability to adapt to change. Responses are made on a 5-point Likert Scale that ranges from "almost never" to "almost always." Respondents describe their perceived level of functioning in the family and their desired level of functioning. The measure has a test-retest reliability of 0.80-0.83. The alpha reliability for cohesion is 0.71 and for adaptability, 0.62. The overall alpha is 0.68, and the measure has fair internal consistency. This measure demonstrates good discriminative validity because it can distinguish between "problem families and non-symptomatic families (Olson et al., 1985, p. 14). The intercorrelation between cohesion and adaptability is 0.03, which indicates that they are two separate factors. The correlation between adaptability and social desirability is zero, but social desirability is a small factor for cohesion. The purpose of using this measure in the study was to determine perceived family functioning. Previous research has shown that high-functioning families were moderate on cohesion and adaptability, while low-functioning families scored at the extremes of cohesion and adaptability. It was hypothesized that

families would be high-functioning if they scored at the extremes on both scales and all family members indicated that their desire is to function at the same level (McCubbin & McCubbin, 1988). The family serves as its own norm base. This is relevant for cultural groups that support family behavior at the extremes (Olson et al., 1985). Therefore, this instrument was used as a measure of family satisfaction because the perceived functioning versus the desired functioning was compared. Three scores were obtained from this measure: family cohesion, family adaptability, and satisfaction with family functioning.

Family Crisis Oriented Personal Evaluation Scales (F-COPES: McCubbin, Olson, & Larsen, 1987). (see Appendix C)

The F-COPES is a 30-item, self-report questionnaire used to assess ways that families cope with stress. The measure uses a 5-point Likert Scale with responses ranging from “strongly disagree” to “strongly agree.” There are five subscales: acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and seek help, and passive appraisal. Higher scores indicate more positive coping and problem solving strategies during times of crisis. The authors calculated norms for this measure with several thousand participants. This measure has good internal consistency and an overall alpha of 0.86. The overall test-retest reliability is 0.81. The alphas for the subscales range from 0.61-0.81, and the test-retest values range from 0.61-0.95. This instrument was designed to measure internal and external coping strategies used by the family. This measure was used in this study to determine if the family uses effective coping strategies and to compare the perceived family coping strategies of the mother and the father of each family. Six scores were obtained from this measure: an overall score of

the use of positive coping and problem solving strategies, acquiring social support, use of reframing, seeking spiritual support, mobilizing the family to acquire and seek help, and the use of passive appraisal of a situation.

Perceived Social Support from Family and from Friends (PSS-FA & PSS-FR: Procidano & Heller, 1983). (see Appendix D and E)

The Perceived Social Support from Family and from Friends is two scales with 20 questions each. These instruments measure perceived social support from family and friends. The participant answers “Yes,” “No,” or “Don’t know” to questions related to quality and quantity of support from family members and friends. The Perceived Social Support from Friends (PSS-Fr) and the Perceived Social Support from Families (PSS-Fa) have a Cronbach’s alpha of 0.88 and 0.90, respectively. The two measures have a 0.40 correlation with each other, which indicates that they are related but measure separate constructs. The PSS-Fa correlated significantly with levels of depression ($r = .49$), whereas the PSS-Fr did not correlate significantly with depression. There was a significant correlation between the PSS-Fr and health status, whereas the PSS-Fa was not related to health status. These measures have good construct validity (Lyons, Perrotta, & Hancher-Kvam, 1988). These questionnaires were used in this study to measure perceived social support because social support has been found to be an important coping mechanism for families of a child with autism (e.g., Gill & Harris, 1991). A score of perceived family social support and perceived friend social support was gathered from these measures.

Semi-Structured Interview (see Appendix A)

The focus of this interview was to gather qualitative data about the family to augment the quantitative data gathered from the questionnaires. The interview provided the experimenter with additional, more personal information. The interviewer began by eliciting a narrative story about how the parents discovered that their child has autism and the difficulties that they confronted in the process. After the narrative story, the interviewer asked specific questions that provided more information about the family's social support, health status, and beliefs about the cause of their child's autism. The interview concluded with an inquiry into any valuable learning experiences that have occurred due to raising a child with autism. The semi-structured interview's primary goal was to provide researchers and clinicians a more comprehensive picture of the difficulties that face families of children with autism.

Procedure

All data were gathered using face-to-face interviews at the family's home. Over the telephone, a trained interviewer set up an appointment to meet with the parents. Each parent filled out an informed consent to express his or her agreement to participate in the research project (see Appendix F). The interviewer administered the FACES-III, the F-COPES, the PSS-Fa, and the PSS-Fr to each parent in random order. Then the experimenter interviewed both parents separately, using a semi-structured interview (see Appendix A). The interviewer provided the parents with the contact information of the principal investigator and his advisor. The participants were welcomed to contact the experimenter for any questions or concerns regarding the experiment.

Results

Scale Data

Table 1 lists the descriptive statistics for the Family Adaptability and Cohesion Evaluation Scales-III (FACES-III), the Family Crisis Oriented Personal Evaluation Scales (F-COPES), and the Perceived Social Support from Family and from Friends (PSS-FA & PSS-FR). All data are from the present sample.

Table 1

Scale Data

Name of Scale	# of Items	Scale Range	Mean (SD)	α
FACES-III	40	122-162	149.10 (10.44)	.74
F-COPES	30	71-138	100.52 (14.79)	.86
PSS-FA	20	1-20	12.81 (5.84)	.91
PSS-FR	20	3-20	14.13 (4.96)	.89

Table 2 lists the descriptive statistics for this sample on cohesion and adaptability (from the FACES-III) and the five subscales of the F-COPES (acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal).

Table 2

Subscale Data

Name of Subscale	# of Items	Scale Range	Mean (SD)	α
Cohesion	10	26-50	40.90 (5.65)	.85
Adaptability	10	11-35	24.86 (4.74)	.66
Social Support	9	13-43	27.98 (6.91)	.86
Reframing	8	18-38	30.00 (4.28)	.71
Spiritual Support	5	8-25	15.85 (4.21)	.74
Mobilizing Help	4	9-20	13.94 (2.94)	.53
Passive Appraisal	4	8-20	15.50 (3.01)	.60

Table 3 lists the number of individuals rating their family on the different levels of cohesion, and Table 4 lists the frequencies for adaptability. There is also the distribution of mother and father ratings of their family on these levels.

Table 3

Sample Frequencies for Levels of Cohesion

Cohesion Level	# of Individuals	# of Mothers	# of Fathers
Disengaged	9	4	5
Separated	12	9	3
Connected	21	5	16
Enmeshed	10	8	2

Table 4

Sample Frequencies for Levels of Adaptability

Adaptability Level	# of Individuals	# of Mothers	# of Fathers
Rigid	6	3	3
Structure	18	10	8
Flexible	14	7	7
Chaotic	14	6	8

Chi-Square Test for Goodness of Fit was conducted to determine if there were any significant differences between frequencies of the levels of cohesion and adaptability of the families with a child with autism in this study and the families in the standardization sample (Olson, Portner, & Lavee, 1985). This statistical test was also used to determine if there were any significant differences in these two samples for the combination of the cohesion and adaptability types. The data from the normed families were the expected values for this sample. For example, a family that rates in the two middle types of cohesion (separated and connected) and adaptability (structured and flexible) are considered “balanced” families. Families who have one rating (cohesion or adaptability) in the middle and the other at the extremes are considered “mid-range” families. Finally, families who have the first or fourth types of cohesion (disengaged and enmeshed) and adaptability (rigid and chaotic) are considered “extreme” families.

Table 5 shows the percentages of the different levels of cohesion for the autism families and the families in the standardization sample. The two samples were not

significantly different ($\chi^2 = 6.21, df = 3, p > .05$). This suggests that families with a child with autism have a similar distribution of types of cohesion as families without children with autism.

Table 5

Comparison of Cohesion Levels between Sampled Families and Normed Families

Cohesion Level	Autism	Normed
Disengaged	17.3	16.3
Separated	23.1	33.8
Connected	40.4	36.3
Enmeshed	19.2	13.6

Note. All numbers are percentage of families in each category.

Table 6 displays the percentages of the different levels of adaptability for the autism families and the families in the standardization sample. These two samples were significantly different ($\chi^2 = 9.38, df = 3, p < .05$). This suggests that families with a child with autism have a different distribution of types of adaptability when compared to families without children with autism. The largest difference was that there were more families in this sample who reported a chaotic style of adaptability than in the normed group.

Table 6

Comparison of Adaptability Levels between Sampled Families and Normed Families

Adaptability Level	Autism	Normed
Rigid	11.5	16.3
Structured	34.6	38.3
Flexible	26.9	29.4
Chaotic	26.9	16.0

Note. All numbers are percentage of families in each category.

Table 7 displays the percentages of the three categories present when cohesion and adaptability types are combined for families with a child with autism and the normed families. The two samples are not significantly different ($\chi^2 = 3.79$, $df = 2$, $p > .05$). This suggests that families with a child with autism have similar types of family systems to those in the standardization sample.

Table 7

Comparison of Family System Levels between Sampled Families and Normed Families

Family System Level	Autism	Normed
Balanced	36.5	48.7
Mid-Range	51.9	46.2
Extreme	11.5	10.9

Note. All numbers are percentage of families in each category.

Hypotheses

A Multivariate Analysis of Variance (MANOVA) (levels of cohesion and adaptability vs perceived social support from family and friends) was conducted to determine if there were significant differences on the two measures of perceived social support (PSS-Fa and PSS-Fr) between the different levels of cohesion (disengaged, separated, connected, and enmeshed) and adaptability (rigid, structured, flexible, and chaotic). This was a test of Hypothesis 1, which stated that moderate levels of family cohesion and adaptability would be significantly related to higher levels of perceived social support. This analysis was based on each individual participant rather than each couple. This test indicated that there were significant differences between the levels of cohesion on measures of perceived social support for the family $F(3, 51) = 5.04, p < .01$ and for friends $F(3, 51) = 3.60, p < .05$. In addition, there were significant differences between the levels of adaptability on perceived social support for the family $F(3, 51) = 2.87, p < .05$, but not for friends.

Tukey's Post-Hoc tests were conducted to determine the nature of these significant results. The means and standard deviations for the scores on the PSS-Fa and PSS-Fr for the four levels of cohesion are listed in Table 8. For the different levels of cohesion, separated and enmeshed families were more likely to perceive family social support than disengaged families ($p < .01, p < .05$, respectively). However, connected families were not significantly different on this measure (cohesion) from the other types of families. The families who were the least cohesive (disengaged) perceived lower social support than two of the more cohesive families (separated and enmeshed), but not the connected families. For perceived social support from friends, enmeshed families

were more likely to perceive high levels of this type of support than disengaged and connected families ($p < .05$ for both). The most cohesive family type perceived more social support from friends than two of the less cohesive family types.

Table 8

Perceived Social Support and Cohesion

Cohesion Level	Social Support from Family	Social Support from Friends
Disengaged	9.44 (6.25)	12.00 (6.30)
Separated	15.33 (3.82)	14.83 (4.53)
Connected	11.90 (6.34)	13.00 (4.56)
Enmeshed	14.70 (5.08)	17.60 (3.34)

The means and standard deviations for the scores on the PSS-Fa and PSS-Fr for the four levels of cohesion are listed in Table 9. For the different levels of adaptability, rigid and structured families were significantly more likely to perceive higher levels of family social support than both flexible and chaotic families ($p < .05$). This suggests that families who are more structured and less adaptable experience greater social support than families with higher levels of adaptability. These results partially support the first hypothesis, which stated that moderate levels of family cohesion and adaptability would be significantly related to higher levels of perceived social support because some of the moderate levels of cohesion and adaptability exhibited higher levels of perceived social support than the extreme levels. However, in several families the extreme levels showed significantly higher levels of perceived social support.

Table 9

Perceived Social Support and Adaptability

Adaptability Level	Social Support from Family	Social Support from Friends
Rigid	17.00 (3.03)	13.50 (4.59)
Structured	14.78 (4.50)	15.17 (4.37)
Flexible	10.78 (6.58)	14.50 (5.44)
Chaotic	10.50 (6.07)	12.71 (5.45)

Bivariate correlations were run to determine if there was a significant relationship between any of the coping strategies measured and participants' satisfaction with their family functioning. This was based on the second hypothesis, which stated that the more coping strategies the family uses the more likely they will be satisfied with the functioning of their family. Because there were no significant relationships, a multiple regression could not be used.

A paired sample t-test was conducted to determine if there was a significant difference within couples' ratings of their family's use of coping mechanisms (based on the total F-COPES score). It was hypothesized that mothers would have higher ratings of the family's coping mechanisms than fathers would. There was not a significant difference within couples' coping scores in this sample. However, there was a significant difference between couples' rating on the Acquiring Social Support subscale of the F-COPES $t(25) = -2.78, p < .05$. This suggests that mothers ($M = 29.9$) are more likely than fathers ($M = 26.0$) to believe that their family seeks social support in times of crisis.

Paired sample t-tests were conducted to determine if there were any significant differences within the ratings of couples on cohesion, adaptability, or their satisfaction with the functioning of the family. It was hypothesized that mothers would be more likely to rate their family as cohesive and adaptable and be more satisfied with the functioning of the family than fathers would. There were no significant differences between the mothers and fathers on these variables in this sample. Finally, a paired samples t-test was run to determine if there were any significant differences within couples' perceived social support from either the family or friends. It was hypothesized that mothers would perceive that they have more social support than fathers would. There was a significant difference between the *perceived social support from friends* within couples $t(25) = -5.22, p < .001$, indicating that the mothers ($M = 16.88$) were more likely than the fathers ($M = 11.38$) to perceive high levels of social support from their friends. There was a significant difference within the *perceived social support from the family* for couples $t(25) = -2.18, p < .05$; the mothers ($M = 14.31$) perceived more social support from the family than fathers ($M = 11.31$) did. Therefore, the final hypothesis was supported.

Additional Findings

A second Multivariate Analysis of Variance (levels of cohesion and adaptability vs family coping mechanisms) was conducted to determine if there were additional significant differences between the different levels of cohesion or adaptability and the other coping mechanisms measured by the F-COPES. There was a significant difference between the levels of cohesion on the total score on the F-COPES (which determines the use of a variety of coping behaviors) $F(3, 51) = 5.04, p < .01$. In addition, there were

several significant differences between the levels of cohesion and the subscales of the F-COPES. These significant differences were found on the Acquiring Social Support subscale $F(3, 51) = 5.12, p < .01$, the Reframing subscale $F(3, 51) = 5.62, p < .01$, and the Passive Appraisal subscale $F(3, 51) = 3.70, p < .05$. There were no significant differences between the different levels of adaptability on the F-COPES or its subscales.

A Tukey's Post-Hoc test was conducted to determine the nature of these significant differences. Table 10 lists the means and standard deviations of the different cohesion levels and scores on the total F-COPES and the three subscales that had significant differences. Passive appraisal is reverse scored, so higher scores indicates less use of this coping style. For the types of cohesion, individuals who rated their family as enmeshed or connected were significantly more likely to use coping mechanisms than disengaged families. Furthermore, enmeshed families were significantly more likely to use coping mechanisms than separated or connected families. This suggests that increasing levels of cohesion is related to increased use of coping behaviors in these families. Supporting this idea, results showed that enmeshed families were significantly more likely to implement acquiring social support as a coping mechanism during times of crisis than connected, separated, or disengaged families. Participants who rated their family as enmeshed, connected, or separated were significantly more likely to use reframing as a coping behavior than disengaged families. Finally, participants who rated their family as disengaged were significantly more likely to implement passive appraisal as a coping mechanism than connected families. This finding indicates that the individuals who rated their family as disengaged were more likely to cope with crises by avoiding the situation (e.g., watching television).

Table 10

Levels of Cohesion and Family Coping Mechanisms

Cohesion Level	Total F-COPES	Social Support	Reframing	Passive Appraisal
Disengaged	90.22 (15.21)	26.00 (6.10)	25.67 (5.61)	13.67 (3.53)
Separated	94.67 (11.94)	25.33 (6.33)	30.67 (2.77)	14.58 (2.94)
Connected	101.43 (12.89)	27.00 (5.98)	30.52 (3.80)	16.52 (2.64)
Enmeshed	114.90 (10.39)	35.00 (6.24)	32.00 (3.13)	16.10 (2.60)

Qualitative Data

The qualitative data were examined from the responses to three main queries: how did you discover that your child had autism and how did your family respond, what do you believe to be the cause of your child's autism, and are there any valuable learning experiences that you have gained from raising a child with autism. Interesting individual responses are included in this section, and the frequency of responses is listed for some answers.

Discovery of Autism

When asked to tell the story of how they came to find out their child had autism, every family reported noticing signs that their child was a little different early on, and viewed the discovery that their child has autism as a life-altering event. However, parents either denied that their child had autism or did not realize that their child's symptoms were characteristics of this disorder. One family indicated, "Everybody knew (our child) had autism but no one told us." Many of the families experienced despair,

sadness, denial, confusion, and anger when they discovered that their child had autism. A few individuals described the experience as a loss comparable to a death in the family. Every family wondered if their child would ever grow up to have a “normal” life or a family or even a job. These families relied on other parents with a child with autism for support and instantly encountered the struggles to obtain services and improve their child’s life. Every family reported attempting to improve their child’s condition with two or more different treatment techniques such as applied analysis of behavior (ABA), gluten- and casein-free diets, or chelation therapy. These parents felt that they were well informed of the controversies related to autism and of its many treatments.

Table 11 lists the frequency of the possible causes of autism listed by the parents. Almost every family provided multiple responses; as a member of one family stated, “We try to blame anything for the cause, sometimes ourselves.” The majority of parents agreed with the scientific field's findings that, to this date, no one has discovered a definitive cause of autism. However, despite the assertion that the thimerosal (mercury) in the Measles, Mumps, and Rubella (MMR) vaccination is not a proven cause of autism, this was the second most frequent cause listed by parents. In nearly every family, parents were in agreement about possible causes of their child's autism. However, there was one mother who did not agree with the father when he explained that the MMR vaccine had a role in causing their child’s autism. In addition, nine families indicated that their child's developmental progress regressed shortly after receiving the vaccine. One family indicated that “the cause (of the autism) weighs heavily on our minds.” Nine parents identified peculiar past or present behaviors (e.g., odd mannerisms or stereotyped behaviors), in themselves (primarily fathers) or other family members, as being related to

their child's autism. Although there were many individuals asserting that the vaccine caused their child's autism, there were seven families who did not believe the vaccine leads to autism. Some parents cited the increase in the prevalence of autism as support for either a genetic or environmental cause. The statement made by one parent, "Autism is definitely more prevalent now," was mirrored by every family.

Table 11

Possible Causes of Autism According to Parents

Causes	Frequency
Genetics	19
Vaccinations	16
Environmental insult	7
Antibiotics/poor immune system	6
Brain abnormality	3
Birth trauma	3
Allergies	1
Self-blame	1

Positive Learning Experiences

Almost every family told of positive learning experiences that were gained from raising a child with autism. Several families indicated that they "appreciate life more in general." They stated that having a child with autism either improved or enhanced

positive personal characteristics such as patience, compassion, and acceptance (especially of others with disabilities). Furthermore, many parents suggested that this experience was a humbling one, and that it opened their eyes to a previously ignored subgroup of the general population. Parents noted that it was a positive experience to learn to be an advocate and researcher for their child. Moreover, one father found that he learned that it was important to “think for himself” and not blindly accept the direction of doctors, school systems, and the government. It seemed that being an advocate and researcher was an empowering experience for many individuals. As part of the hope and patience that they learned from raising their child, 10 families stated that they were excited about minor improvements in development that would have gone unnoticed in their other children. Seven sets of parents suggested that they are better parents because of their child with autism.

Much psychological research on families with a child with autism focuses on the stressful negative effects of raising the child (e.g., Sharpley, Bitsika, & Efremidis, 1997), and that certainly is a big part of the experience. It is also possible, however, that there are also many positive effects of raising a child with autism. Suedfeld (1997) discusses the positive learning experiences that can be gained by experiencing a “traumatic” situation. Although one would expect overwhelming stress from raising a child with autism, many parents reported that their coping mechanisms improved as a result of this experience. For example, one family indicated that they stopped drinking alcohol and smoking cigarettes when they discovered their child had autism. One mother explained her surprise that she and her husband coped successfully with this stressful experience, saying, “We should have been in an institution.” Many families indicated that they

gained some valuable friendships by meeting other parents with a child with autism. Furthermore, some parents stated that their social support network and family relationships strengthened after they discovered that their child had autism. Finally, several families found extensive support from religious organizations and felt that their spirituality was enhanced because of their situation.

Discussion

The purpose of this study was to measure coping mechanisms (focusing on perceived social support), family functioning (cohesion and adaptability), satisfaction with the family's level of functioning in families with a child with autism, and parents' belief about the etiology of autism. In addition, both the mothers' and the fathers' self-reports of family functioning and coping strategies were collected and compared. This research differs from previous research by focusing on discovering differences between mothers and fathers with a child with autism, while implementing a unique data collection method. Based on previous findings (e.g., Bristol, 1984), one might expect that families with a child with autism with moderate levels of cohesion (separated and connected) and adaptability (structured and flexible) would be more likely to possess and implement effective coping mechanisms than individuals who rated their family in the extreme levels of cohesion (disengaged and enmeshed) and adaptability (rigid and chaotic). The first hypothesis stated that moderate levels of family cohesion and adaptability would be significantly related to higher levels of perceived social support. This hypothesis was partially supported by the results, but there were also other interesting and unexpected findings. Individuals who rated their family cohesion as *separated* perceived more social support from their extended family than participants

who rated their family cohesion level as *disengaged*. One would expect that a member of a highly cohesive family would experience more social support from his/her family than would a member of a less cohesive family. In this research, however, individuals who rated their family as *enmeshed*, the most cohesive family type, perceived more social support from the family than did individuals who rated their family as *disengaged*. The enmeshed families also perceived more social support from friends than the disengaged and the connected families. Although it was not expected, it is understandable that enmeshed families have large networks of family and friends who provide positive support. It appears that this finding is in conflict with several researchers who suggest that extreme levels of cohesion in a family (enmeshed in this case) can have negative effects on a child with a disability (e.g., Minuchin, 1974; Seligman & Darling, 1997), but the results from this study cannot say conclusively that these negative effects are not a factor. An enmeshed family can stifle the independence and personal growth of a child with autism. However, it is difficult to deny the importance of social support in decreasing the stress within these types of families (e.g., Konstantareas & Homatidis, 1989). It may also be that families with a child with autism appear enmeshed because of the constant attention that must be directed toward their child. Further, the enmeshed family style may be a reaction to a child with a more severe presentation of autism. Severity of autistic symptoms was not measured in this study and is discussed later as a limitation.

The results from the other coping mechanisms also suggested that less cohesive families do not implement effective coping behaviors when encountering difficult situations. In support of this statement, individuals who rated their family as enmeshed

or connected were more likely to use positive coping mechanisms than disengaged families. In addition, enmeshed families were significantly more likely to use the positive coping behaviors measured by the F-COPES than either separated or connected families. This suggests that increasing levels of cohesion is related to increased use of coping mechanisms. This suggestion is supported by the finding that participants who rated their family as enmeshed were more likely to acquire social support during times of crisis than all of the other levels of cohesion. As stated above, the enmeshed families may employ a large social support network to aid them with their difficulties related to raising a child with autism. The analysis of another subscale of the F-COPES showed that enmeshed, connected, and separated families were significantly more likely to use reframing (viewing conflict or crisis in a positive manner) to cope with difficult situations than disengaged families. The use of reframing is considered to be an important coping mechanism for families with a child with autism (e.g., Ellis, 1987). It is possible that families who can reframe their attitudes about crises can then better cope with these situations. Finally, individuals who rated their family as disengaged were more likely to implement passive appraisal (avoidance of a conflict or crisis within the family) during stressful situations than those from connected families.

Enmeshed families in this sample of families of children with autism were more likely to possess and implement important coping mechanism than families with less cohesion. These very cohesive families may have the resources to deal with the stress related to having a child with autism. Although the creators of the FACES questionnaire (Olson, Portner, & Lavee, 1985) suggest that a well-functioning family has a good balance of cohesion and adaptability, it is possible that families with a large amount of

cohesion can be well-functioning if availability and use of beneficial coping mechanisms is the measure of a well-functioning family. The findings in this study suggest that an enmeshed family may be the optimal level of cohesion for a family with a child with autism. A bigger surprise than the data for the enmeshed families was the findings for the connected families. The connected families did not perceive more social support from family or friends than families from any other level of cohesion and perceived significantly less social support from friends than the enmeshed families. Although a small sample size must be considered in interpreting these results, it is clear that connected families in this sample are not functioning as well as one would expect from families with this moderate level of cohesion.

There were not many differences among the families concerning the levels of adaptability and the coping mechanisms, but those differences were very interesting. Individuals who rated their family as rigid or structured perceived more social support from their extended family than participants who rated their family as flexible or chaotic. This suggests that the families who are more structured and less adaptable perceive significantly more family social support. There were no significant differences on the perceived social support of friends measure or on the F-COPES and its subscales. This is a somewhat surprising finding, as one would expect that families that are more adaptable are better able to engage quickly in positive coping mechanisms when they encounter a stressful situation. However, the different levels of adaptability did not reveal nearly as many significant findings as did cohesion.

The second hypothesis stated that the more coping strategies the family used, the more likely they were to be satisfied with the functioning of their family. There were no

significant differences between participants' satisfaction with the functioning of their family and the coping mechanisms. This was also a surprising finding because it was hypothesized that satisfaction with family functioning would be an important factor in families' ability to cope with having a child with autism. It appears that the majority of the families in this study were satisfied with their family's functioning, so small differences in coping behaviors could not be detected with this independent variable.

In this study, families who were very cohesive (enmeshed) were likely to be rigid or structured on the adaptability continuum. Therefore, the rigid and structured families with a child with autism may benefit from the availability of similar coping mechanisms that were present in the enmeshed families. Additional data would be desirable, but these data suggest that it is more beneficial for families with a child with autism to be less adaptable and more rigid or structured to deal with the hardships of raising their child. Minuchin (1974) suggested that the extreme levels of cohesion and adaptability are harmful to the development of a child with autism. Although it seems like the cross-sectional data in this study contradicts his assertion, a longitudinal study on these families would be necessary to determine the long-term effects of different levels of cohesion and adaptability.

A major goal of this study was to compare the perceptions of the mothers and fathers of children with autism. The third hypothesis stated that mothers would be more likely to rate their family as cohesive and adaptable and be more satisfied with the functioning of the family than fathers would. Interestingly, there were no significant differences within the couples' ratings of their family's total use of coping mechanisms, level of cohesion or adaptability, or their satisfaction with the family functioning. This is

a good sign that the mothers and fathers in this sample agreed on many of the variables. The fourth hypothesis stated that mothers would have higher ratings of the family's coping mechanisms than fathers would (based on the F-COPES). This hypothesis was only partially supported because there were no significant differences between mothers and fathers on the total F-COPES score (use of positive coping mechanisms). However, differences that were found within the couples were that mothers were more likely than fathers to believe that their family seeks social support during times of crisis. This finding is related to the final hypothesis, which stated that mothers would perceive that they have more social support than fathers would. Mothers perceived significantly more social support from their *friends and family* than fathers did.

The high level of social support for the mothers in this sample is a positive finding because mothers of children with autism who perceive more social support experience less somatic problems and depressive symptoms (Gill & Harris, 1991; Gray & Holden, 1992). Although more social support is clearly beneficial, the effects of less perceived social support for the fathers in this study is not clear. Several fathers explained that they lost friends because they felt their friends did not comprehend the struggles associated with raising a child with autism. Others believed that they lost friends because they were not able to spend much time with them. The primary investigator attended a few local autism support group meetings and did not observe any fathers of children with autism at the meetings. Many mothers indicated that their social support came from other mothers they met through support groups or other related functions. It seems that many of the fathers in this study are not receiving a similar

benefit. It may be important to develop more support groups geared for the fathers of these children.

The findings in the current study do not support Krauss' (1993) finding that mothers rate their family as significantly more cohesive and adaptable than do fathers. In addition, Krauss did not discover any significant differences between perceived social support of mothers and fathers, while in this study mothers perceived more social support from family and friends than fathers did. The differences in the results may be explained by Krauss' research sample because he surveyed a sample of families with various childhood disorders rather than focusing on autism. This suggests that the effects on the family may be different when autism is compared with other childhood disorders.

It is possible that a lack of discrepancy between mothers' and fathers' ratings of cohesion and adaptability is positive for the family system. If parents agree on the dynamics of their family, it is likely that they are able to work together more efficiently in completing the difficult task of raising a child with autism. Further, it seems that parents are generally satisfied with the functioning of their family because there were no significant differences between the family functioning levels and satisfaction with this functioning. As stated above, there should be some effort to address the significantly lower perceived social support for the fathers in this sample. Families and practitioners should attempt to protect against fathers' use of avoidance and withdrawal as coping mechanisms by increasing easily accessible sources of support (Houser & Seligman, 1991).

One would expect that a family with a child with autism would function differently than families without such children. However, the results of this study

suggest that there are few differences between the types of families in this sample and a normative sample. There were no significant differences between this sample and a standardized sample in the frequencies of the different types of cohesion and general family system levels. There were significant differences between the different levels of adaptability in the sampled families and the normative population. *The two largest differences were that there were more rigid families in the normative sample and more chaotic families in the autistic sample.* It is not surprising that there are more chaotic families in this study's sample because a family may have to constantly adapt to novel situations when raising a child with autism. The functioning may appear chaotic to others, but it may be beneficial to make effective changes to handle this difficult environment. Rigidity may not be effective because parents with a child with autism will often try unconventional parenting techniques. Further, a rigid family adheres to boundaries that will often prevent the father from aiding the mother in childrearing, thereby increasing the mother and family's stress level (Olson, Russell, & Sprenkle, 1980).

During the interview, every family described feelings of sadness, loss, anger, and desperation when their child was diagnosed with autism. It seems that the mothers were more likely than the fathers to quickly "overcome" these feelings and mobilize their resources to find aid for their child. Many fathers seemed to withdraw for a period after the family received the diagnosis. For the majority of families in this sample, both parents spent much of their time researching causes of autism and possible treatments for their child. Parents described the phenomenon reported by Marshak and Seligman (1993) of changing their attitudes from dislike and ignorance of individuals with disabilities to

advocacy for their child. About 10 families wrote letters to government officials and challenged the beliefs and edicts of school boards. They tirelessly attempted to find various methods to improve the well-being and functioning of their child and their entire family system.

For all families, it was important to cope with having a child with autism by researching and determining a possible cause of their child's autism. Gray (1995) found that many parents suggested that some type of birth trauma caused their child's autism. Several years later, Furnham and Buck (2003) found that more parents expressed their belief that there is a genetic cause of the disorder. However, there continued to be a large number of individuals who thought that autism was a direct result of a birth trauma or brain damage. In this sample, the majority of parents agreed with the current literature (Mackowiak, 2000), which suggests that there is a genetic cause for autism; however, there were a small group of individuals who thought that a birth trauma or brain abnormality caused their child's autism. It seems like this etiological explanation from parents is becoming less prevalent with the increase of research available on the Internet for these parents. However, many parents continue to believe that the MMR vaccination directly caused or triggered a reaction that eventually led to autistic symptoms, despite scientific evidence that does not support this as a possible etiology. This is a contentious point for many parents, as they believe the scientific community is missing important evidence, and these parents often present compelling evidence that suggests they may be correct. The undiscovered cause of autism is another struggle that will continue to face these parents, as they attempt to find some meaning and explanation for their child's developmental disorder.

As discussed in the introduction, it is important, for coping, how the family conceptualizes the event of having a child with autism (McCubbin & McCubbin, 1987). This conceptualization is an integral part of their ability to cope with the struggles of raising a child with autism. If parents dwell on a negative attribution of this event, it is likely that they will cope poorly with the situation. In this study, nearly every parent was able to describe a positive learning experience gained from raising his or her child. Many parents indicated that their lives improved greatly as a result of having a child with autism. They noticed that they became more patient, compassionate, humble, and accepting. It seems that these parents took little for granted and made every effort to view their situation in a positive light. Instead of struggling to cope with this stressful situation, many parents stated that their coping mechanisms improved, and they had more meaningful relationships with friends and family members. Every family seemed to find the experience of telling their story as cathartic, and some parents were surprised to discover that they were able to personally grow and raise a strong family, despite the everyday struggles associated with having a child with autism.

Limitations and Conclusions

There are several limitations to this study, so the findings should be interpreted with caution. As with most studies on families with a child with autism, the current study is plagued by a relatively small sample size. Nevertheless, a sample of 26 families was exhaustively surveyed and interviewed. There were several issues that could have been assessed. Information gathered on the severity of the child's autistic presentation could have provided significant and interesting results. It is possible that the severity of the disorder could predict the use and availability of coping mechanisms and the level of

cohesion and adaptability (e.g., severe presentations are related to rigidity). Another variable that was not present in our data collection was a measure of family stress level. It is likely that different levels of stress would create significant relationships with the other variables measured in the study. It was assumed that all parents of children with autism experience significant levels of stress (e.g., Sivberg, 2002), but it is likely that there are differences between stress levels from family to family. The principal investigator did not want to take more of the participants' precious time by including several more questionnaires in the protocol, so these measures were not included in the current investigation. Future studies would benefit from inclusion of measures of autistic symptoms and family stress.

Another important study would be a longitudinal investigation of how family system characteristics and family coping mechanisms affect the development of the child. However, besides the obvious difficulties of a longitudinal study, it would be difficult to control for the different symptom severity and presentations of autistic spectrum disorders. Although there were some general similarities between the children in the study, each child had a unique presentation of the disorder.

There were many interesting and some surprising findings that resulted from this study. For example, it was discovered that the enmeshed (strongly cohesive) families have available to them and use more positive coping mechanisms than the other levels of cohesion. This data informs the theory that enmeshed families can negatively affect an autistic child's development. At the very least, it seems that the family stress may be lower for the enmeshed families. It was surprising that there were no significant relationships between an individual's satisfaction with the functioning of his/her family

and any other variables. It was hypothesized that this variable would produce some significant differences, and it was a variable that has not been analyzed in any studies with families of a child with autism. It is not clear if this was a function of a small sample size or that satisfaction with family functioning is not an important factor.

It is refreshing to discover that almost every parent was able to describe a positive learning experience from having a child with autism. This suggests that a “whatever does not kill you makes you stronger” belief may be involved in the difficult situation of raising a child with autism. Many parents found that some areas of their life were significantly improved because of their experiences raising their child. It also was observed that these parents are involved in trying to improve their child’s life through constant research and, for some, advocacy work. Many parents complained about the inadequacy of support groups, struggles with the government’s lack of support of funding and research, and unhelpful and unqualified schools, doctors, and clinicians. If medical and mental health professionals and these institutions are more attentive and helpful to these families, parents can spend less time searching for services and with advocacy efforts and more time seeking coping resources and helping their child to develop. The public’s awareness of autism may be increasing on a daily basis, yet these families continue to feel that they are a hidden demographic that is easily ignored and discounted by individuals in helping professions.

References

- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders*, (4th ed. text revision). Washington DC: Author.
- Beckman, P. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *American Journal of Mental Retardation*, 95, 585-595.
- Bristol, M. M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler & G. B. Mesibov (Eds), *The effects of autism on the family* (pp. 289-310). New York: Plenum Press.
- Crnic, K. A., Friedrich, N. W., & Greenburg, M. T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. *American Journal of Mental Deficiency*, 88, 125-138.
- DeMyer, M. K. (1979). *Parents and children in autism*. Washington, DC: V. H. Winston.
- Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality*, 2, 97-110.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37, 39-52.
- Ellis, A. (1987). Rational emotive therapy: Current appraisal and future directions. *Journal of Cognitive Psychotherapy*, 1, 73-86.
- Fisman, S. N., Wolf, L. C., & Noh, S. (1989). Marital intimacy in parents of exceptional

- children. *Canadian Journal of Psychiatry*, 34, 519-525.
- Fombonne, E. (2003). The prevalence of autism. *Journal of the American Medical Association*, 289, 87-89.
- Frey, K. S., Greenberg, M. T., & Fewell, R. R. (1989). Stress and coping among parents of handicapped children: A multidimensional approach. *American Journal of Mental Retardation*, 94, 240-249.
- Furnham, A., & Buck, C. (2003). A comparison of lay-beliefs about autism and obsessive-compulsive disorder. *International Journal of Social Psychiatry*, 49, 287-307.
- Gill, M. J., & Harris, S. L. (1991). Hardiness and social support as predictors of psychological discomfort in mothers of children with autism. *Journal of Autism and Developmental Disorders*, 21, 407-416.
- Gray, D. E. (1994). Coping with autism: Stresses and strategies. *Sociology of Health & Illness*, 16, 275-300.
- Gray, D. E. (1995). Lay conceptions of autism: Parents' explanatory models. *Medical Anthropology*, 16, 99-118.
- Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability*, 27, 215-222.
- Gray, D. E., & Holden, W. (1992). Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities*, 18, 83-93.
- Halligan, S. L., Herbert, J., Goodyer, I. M., & Murray, L. (2004). Exposure to postnatal

- depression predicts elevated cortisol in adolescent offspring. *Biological Psychiatry*, 55, 376-381.
- Hornby, G. (1994). *Counseling in child disability: Skills for working with parents*. London: Chapman & Hall.
- Houser, R., & Seligman, M. (1991). A comparison of stress and coping by fathers of adolescents with mental retardation and fathers of adolescents without mental retardation. *Research in Developmental Disabilities*, 12, 251-260.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217-250.
- Kanner, L. (1992). Follow-up study of eleven autistic children originally reported in 1943. *Focus on Autistic Behavior*, 7, 1-11.
- Kleinman, A. (1980). *Patients and healers in the context of culture*. Berkeley: University of California Press.
- Koegel, R. L., Schreibman, L., O'Neill, R. E., & Burke, J. C. (1983). The personality and family-interaction characteristics of parents of autistic children. *Journal of Consulting and Clinical Psychology*, 51, 683-692.
- Konstantareas, M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 30, 459-470.
- Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal of Mental Retardation*, 97, 393-404.
- Liwag, M. (1989). Mothers and fathers of autistic children: An exploratory study of family stress and coping. *Philippine Journal of Psychology*, 22, 3-16.

- Lyons, J. S., Perrotta, P., & Hancher-Kvam, S. (1988). Perceived social support from family and friends: Measurement across disparate samples. *Journal of Personality Assessment, 52*, 42-47.
- Mackowiak, M. (2000). Aetiology of autism: Focus on the biological perspective. *Early Child Development and Care, 160*, 77-84.
- Marshak, L. E., & Seligman, M. (1993). *Counseling persons with disabilities: Theoretical and clinical perspectives*. Austin, TX: Pro-Ed.
- McCubbin, H., Larson, A., & Olson, D. (1987). F-COPES Family Crisis Oriented Personal Scales. In H. McCubbin & A. Thompson (Eds.), *Family assessment inventories for research and practice*. Madison, WI: University of Wisconsin, Madison.
- McCubbin, H., & McCubbin, M. (1987). Family stress theory and assessment: The T-Double ABCX Model of Family Adjustment and Adaptation. In H. McCubbin & A. Thompson (Eds.), *Family assessment inventories for research and practice*. Madison: University of Wisconsin, Madison.
- McCubbin, M. A., & McCubbin, H. I. (1988). Family systems assessment. In P. Karoly (Ed.), *Handbook of child health assessment: Biopsychological perspectives*. (pp. 227-261). Oxford, England: John Wiley & Sons.
- McCubbin, H., & Patterson, J. M. (1981). *Systematic assessment of family stress, resources, and coping: Tools for research, education and clinical intervention*. St. Paul: University of Minnesota.
- McCubbin, H., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage and Family Review, 6*, 7-37.

- McKinney, B., & Peterson, R. A. (1987). Predictors of stress in parents of developmentally disabled children. *Journal of Pediatric Medicine, 12*, 133-150.
- Minuchin, S. (1974). *Families and family therapy*. Cambridge, MA: Harvard University Press.
- Moes, D., Koegel, R., Schreibman, L., & Loos, L. (1992). Stress profiles for mothers and fathers of children with autism. *Psychological Reports, 71*, 1272-1274.
- Morgan, S. B. (1988). The autistic child and family functioning: A developmental-family systems perspective. *Journal of Autism and Developmental Disorders, 18*, 263-280.
- Olson, D. H., Portner, J., & Lavee, Y. (1985). *FACES III*. Family Social Science, University of Minnesota, St. Paul.
- Olson, D. H., Russell, C. S., & Sprenkle, D. H. (1980). Circumplex model of marital and family systems II: Empirical studies and clinical intervention. In J. P. Vincent (Ed.), *Advances in family intervention assessment and theory* (Vol. 1, pp 129-179). Greenwich, CT: JAI Press.
- Patterson, J. M. (1988). Chronic illness in children and the impact on families. In C. Chilman, E. Nunnally, & E. Cox (Eds.), *Chronic illness and disability* (pp. 69-107). Beverly Hills: Sage.
- Patterson, J. M. (1991). A family systems perspective for working with youth with disability. *Pediatrician, 18*, 129-141.
- Procidano, M. E., & Heller, K. (1983). Measures of perceived social support from friends and from family: Three validation studies. *American Journal of Community Psychology, 11*, 1-24.

- Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism. In Marital stress and support coping. *Journal of Autism and Developmental Disorders*, 33, 383-394.
- Sameroff, A. J. (1990). Neo-environmental perspectives on developmental theory. In R. M. Hodapp, J. A. Burack, & E. Zigler (Eds.), *Issues in the developmental approach to mental retardation* (pp. 93-113). Cambridge: Cambridge University Press.
- Schall, C. (2000). Family perspectives on raising a child with autism. *Journal of Child and Family Studies*, 9, 409-423.
- Seligman, M., & Darling, R. B. (1997). *Ordinary families, special children* (2nd ed.). New York: Guilford Press.
- Sharpley, C. F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual & Developmental Disability*, 22, 19-28.
- Singer, G. H. S., & Powers, L. E. (1993). *Families, disability, and empowerment*. Baltimore: Brookes.
- Sivberg, B. (2002). Family system and coping behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism*, 6, 397-409.
- Suedfeld, P. (1997). Homo invictus: The indomitable species. *Canadian Psychology*, 38, 164-173.
- Turnbull, A. P., & Turnbull, H. R. (1986). *Families, professionals, and exceptionality*.

Columbus, OH: Merrill.

Werner, E. E., & Smith, R. S. (1982). *Vulnerable but invincible: A longitudinal study of resilient children and youth*. New York: McGraw-Hill.

Wilson, R. S. (1985). Risk and resilience in early mental development. *Developmental Psychology*, *21*, 795-805.

Appendices

Appendix A

Interview

- Begin by asking the parents to tell the story of the birth of the child with autism and how they found out their child had autism.
- What do you believe to be the cause of your child's autism?
- Are there any valuable learning experiences that you have gained from raising a child with autism?

Appendix B

FACES-III

Please use the following scale to answer both sets of questions:

- 1 = Almost never
- 2 = Once in a while
- 3 = Sometimes
- 4 = Frequently
- 5 = Almost always

DESCRIBE YOUR FAMILY NOW:

1. Family members ask each other for help.
2. In solving problems, the children's suggestions are followed.
3. We approve of each other's friends.
4. Children have a say in their discipline.
5. We like to do things with just our immediate family.
6. Different persons act as leaders in our family.
7. Family members feel closer to other family members than to people outside the family.
8. Our family changes its way of handling tasks.
9. Family members like to spend free time with each other.
10. Parent(s) and children discuss punishment together.
11. Family members feel very close to each other.
12. The children make the decisions in our family.
13. When our family gets together for activities, everybody is present.
14. Rules change in our family.
15. We can easily think of things to do together as a family.
16. We shift household responsibilities from person to person.
17. Family members consult each other on their decisions.
18. It is hard to identify the leader(s) in our family.
19. Family togetherness is very important.
20. It is hard to tell who does which household chores.

IDEALLY, HOW WOULD YOU LIKE YOUR FAMILY TO BE:

21. Family members would ask each other for help.
22. In solving problems, the children's suggestions would be followed.
23. We would approve of each other's friends.
24. The children would have a say in their discipline.
25. We would like to do things with just our immediate family.
26. Different persons would act as leaders in our family.
27. Family members would feel closer to each other than to people outside the family.
28. Our family would change its way of handling tasks.
29. Family members would like to spend free time with each other.

30. Parent(s) and children would discuss punishment together.
31. Family members would feel very close to each other.
32. Children would make the decisions in our family.
33. When our family got together, everybody would be present.
34. Rules would change in our family.
35. We could easily think of things to do together as a family.
36. We would shift household responsibilities from person to person.
37. Family members would consult each other on their decisions.
38. We would know the leader(s) was (were) in our family.
39. Family togetherness would be very important.
40. We could tell who does which household chores.

Appendix C F-COPES

Purpose:

The Family Crisis Oriented Personal Evaluation Scales are designed to record effective problem-solving attitudes and behavior, which families develop to respond to problems or difficulties.

Directions:

First, read the list of response choices on at a time.

Second, decide how well each statement describes your attitudes and behaviors in response to problems or difficulties. If the statement describes your response *very well*, then circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then circle the number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response. Use the following five-point scale:

Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree
1	2	3	4	5

WHEN WE FACE PROBLEMS OR CRISES IN OUR FAMILY, WE RESPOND BY:

- | | | | | | |
|--|---|---|---|---|---|
| 1. Sharing our difficulties with relatives | 1 | 2 | 3 | 4 | 5 |
| 2. Seeking encouragement and support from friends. | 1 | 2 | 3 | 4 | 5 |
| 3. Knowing we have the power to solve major problems. | 1 | 2 | 3 | 4 | 5 |
| 4. Seeking information and advice from persons in other families who have faced the same or similar problems | 1 | 2 | 3 | 4 | 5 |
| 5. Seeking advice from relatives (grandparents, etc.). | 1 | 2 | 3 | 4 | 5 |
| 6. Seeking assistance from community agencies and programs designed to help families in our situation. | 1 | 2 | 3 | 4 | 5 |

WHEN WE FACE PROBLEMS OR CRISES IN OUR FAMILY, WE RESPOND BY:

- | | | | | | |
|---|---|---|---|---|---|
| 7. Knowing that we have the strength within our own family to solve our problems. | 1 | 2 | 3 | 4 | 5 |
| 8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.). | 1 | 2 | 3 | 4 | 5 |
| 9. Seeking information and advice from the family doctor. | 1 | 2 | 3 | 4 | 5 |
| 10. Asking neighbors for favors and assistance. | 1 | 2 | 3 | 4 | 5 |
| 11. Facing the problems “head-on” and trying to get solutions right away. | 1 | 2 | 3 | 4 | 5 |
| 12. Watching television. | 1 | 2 | 3 | 4 | 5 |
| 13. Showing that we are strong. | 1 | 2 | 3 | 4 | 5 |
| 14. Attending church services. | 1 | 2 | 3 | 4 | 5 |
| 15. Accepting stressful events as a fact of life. | 1 | 2 | 3 | 4 | 5 |
| 16. Sharing concerns with close friends. | 1 | 2 | 3 | 4 | 5 |
| 17. Knowing luck plays a big part in how well we are able to solve family problems. | 1 | 2 | 3 | 4 | 5 |
| 18. Exercising with friends to stay fit and reduce tension. | 1 | 2 | 3 | 4 | 5 |
| 19. Accepting that difficulties occur unexpectedly. | 1 | 2 | 3 | 4 | 5 |
| 20. Doing things with relatives (get-togethers, dinners, etc.). | 1 | 2 | 3 | 4 | 5 |
| 21. Seeking professional counseling and help for family difficulties. | 1 | 2 | 3 | 4 | 5 |
| 22. Believing we can handle our own problems. | 1 | 2 | 3 | 4 | 5 |
| 23. Participating in church activities. | 1 | 2 | 3 | 4 | 5 |

WHEN WE FACE PROBLEMS OR CRISES IN OUR FAMILY, WE RESPOND BY:

- | | | | | | |
|---|---|---|---|---|---|
| 24. Defining the family problems in a more positive way so that we do not become too discouraged. | 1 | 2 | 3 | 4 | 5 |
| 25. Asking relatives how they feel about problems we face. | 1 | 2 | 3 | 4 | 5 |
| 26. Feeling that no matter what we do to prepare, we will have difficulty handling problems. | 1 | 2 | 3 | 4 | 5 |
| 27. Seeking advice from a minister. | 1 | 2 | 3 | 4 | 5 |
| 28. Believing if we wait long enough, the problem will go away. | 1 | 2 | 3 | 4 | 5 |
| 29. Sharing problems with neighbors. | 1 | 2 | 3 | 4 | 5 |
| 30. Having faith in God. | 1 | 2 | 3 | 4 | 5 |

Appendix D
Perceived Social Support-Family

Directions: The statements that follow refer to feelings and experiences that occur to most people at one time or another in their relationships with families. For each statement there are three possible answers: Yes, No, Don't Know. Please circle the answer you choose for each item.

- | | | | |
|-----|----|------------|---|
| Yes | No | Don't Know | 1. My family gives me the moral support I need. |
| Yes | No | Don't Know | 2. I get good ideas about how to do things or make things from my family. |
| Yes | No | Don't Know | 3. Most other people are closer to their family than I am. |
| Yes | No | Don't Know | 4. When I confide in the members of my family who are closest to me, I get the idea it makes them uncomfortable. |
| Yes | No | Don't Know | 5. My family enjoys hearing about what I think. |
| Yes | No | Don't Know | 6. Members of my family share many of my interests. |
| Yes | No | Don't Know | 7. Certain members of my family come to me when they have problems or need advice. |
| Yes | No | Don't Know | 8. I rely on my family for emotional support. |
| Yes | No | Don't Know | 9. There is a member of my family I could go to in were just feeling funny about it later. |
| Yes | No | Don't Know | 10. My family and I are very open about what we think about things. |
| Yes | No | Don't Know | 11. My family is sensitive to my personal needs. |
| Yes | No | Don't Know | 12. Members of my family come to me for emotional support. |
| Yes | No | Don't Know | 13. I have a deep sharing relationship with a number of friends. |
| Yes | No | Don't Know | 14. Members of my family are good at helping me solve problems. |
| Yes | No | Don't Know | 15. Members of my family get good ideas about how to do things or make things from me. |
| Yes | No | Don't Know | 16. When I confide in members of my family, it makes me feel uncomfortable. |
| Yes | No | Don't Know | 17. Members of my family seek me out for companionship. |
| Yes | No | Don't Know | 18. I think that my family feels that I'm good at helping them solve problems. |
| Yes | No | Don't Know | 19. I don't have a relationship with a member of my family that is as close as other people's relationships with family members.. |
| Yes | No | Don't Know | 20. I wish my family were much different. |

Appendix E
Perceived Social Support-Friends

Directions: The statements that follow refer to feelings and experiences that occur to most people at one time or another in their relationships with friends. For each statement there are three possible answers: Yes, No, Don't Know. Please circle the answer you choose for each item.

- | | | | |
|-----|----|------------|---|
| Yes | No | Don't Know | 1. My friends give me the moral support I need. |
| Yes | No | Don't Know | 2. Most other people are closer to their friends than I am. |
| Yes | No | Don't Know | 3. My friends enjoy hearing about what I think. |
| Yes | No | Don't Know | 4. Certain friends come to me when they have problems or need advice. |
| Yes | No | Don't Know | 5. I rely on my friends for emotional support. |
| Yes | No | Don't Know | 6. If I felt that one or more of my friends were upset with me, I'd just keep it to myself. |
| Yes | No | Don't Know | 7. I feel that I'm on the fringe in my circle of friends. |
| Yes | No | Don't Know | 8. There is a friend I could go to if I were just feeling down, without feeling funny about it later. |
| Yes | No | Don't Know | 9. My friends and I are very open about what we think about things. |
| Yes | No | Don't Know | 10. My friends are sensitive to my personal needs. |
| Yes | No | Don't Know | 11. My friends come to me for emotional support. |
| Yes | No | Don't Know | 12. My friends are good at helping me solve problems. |
| Yes | No | Don't Know | 13. I have a deep sharing relationship with a number of friends. |
| Yes | No | Don't Know | 14. My friends get good ideas about how to do things or make things from me. |
| Yes | No | Don't Know | 15. When I confide in friends, it makes me feel uncomfortable. |
| Yes | No | Don't Know | 16. My friends seek me out for companionship. |
| Yes | No | Don't Know | 17. I think that my friends feel that I'm good at helping them solve problems. |
| Yes | No | Don't Know | 18. I don't have a relationship with a friend that is as intimate as other people's relationships with friends. |
| Yes | No | Don't Know | 19. I've recently gotten a good idea about how to do something from a friend. |
| Yes | No | Don't Know | 20. I wish my friends were much different. |

Appendix F Informed Consent

1. **Purpose of the Study:** The purpose is to examine the relationship between coping mechanisms and family functioning in parents with a child with autism.
2. **Participation Withdrawal or Refusal to Participate:** Taking part in this study is voluntary. You may refuse to participate or withdraw from the research at any time without any penalty.
3. **Description of the Procedures:** You will fill out four questionnaires. The questionnaires will inquire about various aspects of your family and your use of coping mechanisms. After completing the questionnaires, you will be interviewed by the experimenter. The interview will focus on the experiences of raising a child with autism. The entire process will take about an hour to an hour and a half.
4. **Anonymity:** Please do not put your name anywhere on the questionnaires, so your answers remain anonymous. This will allow the results of the questionnaire to be kept confidential because there will be no identifying information attached to the questionnaires.
5. **Expected Risks of the Study:** There are no known risks for participating in the study. Some of the questions may be troubling to you, but not more so than normal discussion of these issues. If you would like to talk to anyone about uncomfortable reactions you have from the experiment, please contact the EMU Psychology Clinic as an option for low cost services (734-487-4987).
6. **Expected Benefits of the Study:** Your participation in the research may provide key information about effective coping behaviors that can improve the functioning of families with a child with autism. This information could be used in workshops for doctors, psychologists, and parents in order to teach ways to improve family functioning by implementing appropriate coping mechanisms. You may become aware of some additional coping strategies as a result of reading the findings of the study. In addition, your family will receive a ten dollar gift certificate for pizza.
7. **Use of Research Results:** The research in this study will be published in psychological journals and presented at autism conferences. The data published will not be individual results so the data cannot be linked back to individual participants' identities. You can contact the Principal Investigator Matthew Altieri (maltiere@emich.edu) to receive a copy of the results of the study. You can also contact Matthew Altieri's supervisor, Dr. Silvia von Kluge if you have any questions or comments concerning the research at svonkluge@emich.edu.
8. **If You Have Questions or Comments:** Please contact the researcher, Matthew Altieri, at maltiere@emich.edu. You may also contact the Psychology Department Research Review Committee Chair, Dr. Karen Saules, at (734) 487-4988, or ksaules@emich.edu.

I understand my rights as a research participant and I voluntarily consent to participate in this study. I have received a copy of this informed consent form, and I understand what the study is about and how and why it is being conducted.

Participant's Signature

Date

Signature of Principal Investigator

Date

