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STRESS AND COPING IN FAMILIES WITH A CHILD WITH AUTISM

Thesis

Submitted to

**The College of Arts and Sciences of the
UNIVERSITY OF DAYTON**

in Partial Fulfillment of the Requirements for

The Degree

Master of Arts in Clinical Psychology

by

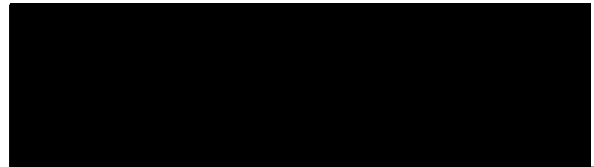
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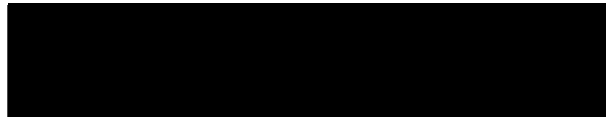
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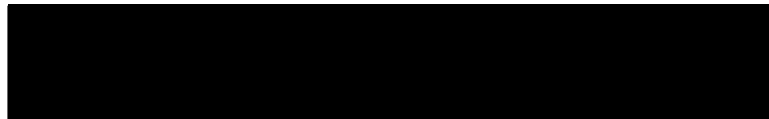
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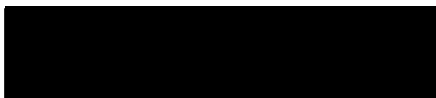


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ABSTRACT

STRESS AND COPING IN FAMILIES WITH A CHILD WITH AUTISM

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Raising a child with Autism creates significant stress for caregivers. This study explored the relation between the severity of autistic symptoms and parental stress levels and resulting mental health difficulties. This study also aimed to identify more effective coping strategies by examining current parental strategies for coping (e.g., task-oriented, emotion-oriented, and avoidance-oriented), as well as parenting styles and differences in parenting between the child with Autism and his or her sibling. It was hypothesized that the severity of autistic symptoms would be related to parental symptomatology and stress. It was also hypothesized that there were mediating variables in coping with stress, including an authoritative parenting style and task-oriented coping strategies which would reduce the amount of stress the caregivers experience. Additionally, it was predicted that parents would use different styles of parenting between their children with Autism and siblings. Results found a direct relationship between the severity of autistic symptoms and parental stress and symptomatology. Task-oriented and social diversion coping strategies were found to be more effective methods of coping, whereas emotion-oriented and distraction coping strategies were related to greater stress and

symptomatology. This study also found that caregivers report using a greater number of parenting strategies with siblings; however, they do not use more of one type of parenting style with either child. Parents use greater authoritative parenting with both children than authoritarian or permissive parenting styles. The results may be helpful in training professionals and educating caregivers in order to reduce parental stress resulting in better mental health and overall well-being.

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CHAPTER I

INTRODUCTION

The notion that raising a child with a developmental disability constitutes a significant stressor for caregivers is almost self-evident. In fact, research has shown that parents of children with a developmental disability report disproportionately greater levels of stress than parents of children without a developmental disability (e.g., Erguner-Tekinalp & Akkok, 2004; Hastings et al., 2005; Perry, Harris & Minnes, 2005; Weiss, 2002). Autism is a pervasive developmental disorder characterized by severe impairment in several critical areas of functioning. Children with Autism possess difficulties in reciprocal social skills, communication skills, and symbolic or imaginative play, and are characterized by stereotyped behaviors, interests, and activities (American Psychiatric Association, 2000). Autism typically impacts more areas of functioning than other developmental disabilities, which may lead to increased stress for the caregivers. The parenting style utilized by the caregivers may serve as a coping response to stress and may differ between children within the family. Because raising a child with Autism places stress on the family as a whole, the entire family system, including siblings, may be affected (Sanders & Morgan, 1997). The purpose of this study is to examine the role of parenting style as a means for coping with the stress of raising a child with Autism, as well as potential differences in parenting style with siblings.

Autism

According to the American Psychiatric Association (2000), the essential features of Autistic Disorder include the presence of markedly abnormal or impaired development in the following areas: social interaction (e.g., lack of social or emotional reciprocity), communication (e.g., delay in or lack of the development of spoken language), and a markedly restricted repertoire of activity and interests (e.g., persistent preoccupation with parts of objects). The disturbance must also include delays or abnormal functioning in at least one of the following areas prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play. Although children with Autism display many other critical difficulties, Bebko, Konstantareas and Springer (1987) have noted that these characteristic symptoms are often rated as the most severe and stressful characteristics of Autism by both families of children with Autism and professionals in the field. Specifically, language difficulties, social impairment, and emotional inappropriateness are reported as remarkably more severe than other symptoms and have been frequently recognized in the literature as problematic behaviors for the child and the family. This may be due to the lack of reciprocity in social and emotional behaviors experienced by the caregiver, as well as a more pessimistic view of the child's future.

Manifestations of Autistic Disorder vary greatly depending on the developmental level and chronological age of the child (American Psychiatric Association, 2000). Associated features of the disorder may include an additional diagnosis of Mental Retardation, which ranges from mild to profound, and may exhibit itself as abnormalities in the development of cognitive skills. A range of behavioral symptoms, such as

hyperactivity, impulsivity, aggressiveness, self-injurious behaviors, and temper tantrums may also be present. Early research estimated rates of the disorder as 5 to 10 cases per 10,000 individuals (e.g., Bryson, Clark & Smith, 1988; Gillberg, Steffenburg & Schaumann, 1991; Ritvo et al., 1990). However, recent studies have produced much higher estimates of 3.2 to 4 cases per 1,000 individuals for Autism, and 6.7 in 1,000 for Autism Spectrum Disorders (ASD) (e.g., Bertrand et al., 2001; Yeargin-Allsopp et al., 2003). ASD refers to a continuum of disorders within Autism, including Asperger's Disorder and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). It is unclear whether the higher reported rates indicate differences in the methodology of diagnosis or an increased frequency of the disorder (American Psychiatric Association, 2000). Regardless of the cause, increasingly more children and families are affected by Autism and consequently must cope with the stress associated with the disorder.

Stress

Stress is often a significant issue for families of children with disabilities due to the emergence of unique difficulties for the caregivers and a resulting complicated family system (Keller & Honig, 2004). Parenting a child with a developmental disability is even more demanding than other disabilities because it is a long-term, intense, and ambiguous stressor with issues about the disorder often uncertain (Weiss, 2002). Research indicates that it is easier to cope with a stressor when the nature of the stressor and its implications are clear, implying that it is more difficult to cope with unclear stressors (Hoff, Mullins, Chaney, Hartman & Domek, 2002; Perry et al., 2005). Thus, it is not surprising that increased stress has been reported in families of children whose disabilities were of unknown etiology, such as Autism, compared to other disabilities for which the etiology

is well established, such as Down Syndrome. Because there is considerable evidence that high levels of stress are associated with the task of caring for a child with Autism (e.g., Bouma & Schweitzer, 1990; Perry, 2005; Weiss, 2002), it is important to establish a definition of stress that can be clinically applied to families of children with Autism.

Over the past 40 years, researchers and clinicians from a multitude of disciplines have brought tremendous diversity to the understanding and measurement of stress, as well as to clinical work with families (Perry, 2005). However, there remains a lack of consensus regarding the conceptualization of stress and the selection of measures used. Therefore, different definitions of stress can be identified, each with its own body of literature and each with its own application to families of children with Autism. Several of these definitions and models of stress are presented below.

The first model conceptualizes stress as “the physiological and psychological reactions that an organism goes through, usually in stages, to adapt to a stressful situation” (Perry, 2005). This definition of stress has been clinically applied to families of children with Autism through the use of established grieving models. When faced with having a child with a disability, parents may react in stages of shock, denial, anger, bargaining, working through, and adjustment, which is similar to the stages of grief (Keller & Honig, 2004). Because adjustment for the parents of the child with Autism may only be temporary, the grieving process may occur intermittently throughout the life of the family (Perry, 2005).

A second model of stress is referred to as the “stressful life events” paradigm which suggests that stressful life events have a negative impact on mental and physical health (Perry, 2005). For example, the emotional turmoil experienced by the caregiver of

a child with Autism can result in a variety of mental illnesses, such as depression and anxiety (Higgins, Bailey & Pearce, 2005). The application of this definition can be illustrated through differences in the effectiveness of coping in families of children with Autism, with some families coping well and reporting positive effects, while others report significant stress and strain (Perry, 2005). Although this model has been researched at length, there is often a weak relationship between a particular stressful event and a particular outcome due to the effect of other variables (e.g., support networks, coping strategies) not measured by life events checklists in these families.

Another approach to the conceptualization of stress is associated with a “resource imbalance” between the demands of a situation and an individual’s resources or coping mechanisms (Perry, 2005). With regard to families of children with Autism, this approach suggests that stress is more than just a single life event (e.g., the disabled child) or a series of daily frustrations. Stress depends on the individual’s ability to cope, available resources, and social support. With the presence of these factors, negative consequences of stress may be alleviated.

Although all of the above models of stress are used, the conceptualization of stress most frequently referenced in the literature is known as the “daily hassles” paradigm. This approach suggests that the cumulative effect of everyday annoyances associated with caretaking causes stress, and not necessarily a major life event (Perry, 2005). This model of stress has been researched extensively in families of children with Autism and is exemplified in many measures of parenting stress, such as the Questionnaire on Resources and Stress (QRS). The QRS takes this approach by assessing parent perceptions of realistic features of the child (e.g., “my child needs help using the

bathroom”) rather than measuring the degree to which the parent perceives an event as stressful. Therefore, the “daily hassles” conceptualization of stress will be utilized in the present study due to its frequent use with families of children with developmental disabilities and the administration of the QRS in this study.

Sources of Stress

Although the stress of raising a child with Autism may originate from a variety of factors, some of these are of greater importance than others. Sharpley, Bitsika and Efremidis (1997) report that three of the most stressful factors of raising a child with Autism include: (1) the permanency of the condition, (2) the lack of acceptance of autistic behaviors by society and family members, and (3) low levels of support provided by health care services and other social services. These issues will each be addressed further.

The permanency of Autism is associated with stress due to issues of ongoing dependency and limits on family activities (Higgins et al., 2005). The child’s future and autonomy are factors that may contribute to the stress associated with life long dependency (Weiss, 2002). In families with a developmentally disabled child, the degree and severity of the stress is often related to the amount of care the child requires (Bouma & Schweitzer, 1990), with higher levels of stress associated with the task of caring for a highly dependent child (Duarte, Bordin, Yazigi & Mooney, 2005). For instance, stress may arise from concerns regarding the child’s ability to live independently or future decisions once the parents can no longer care for the child. Additionally, behavioral problems of the child with Autism may result in extreme disruptions in daily family life (Bouma & Schweitzer, 1990). For example, aggressive and self-injurious behavior,

impulsivity, hyperactivity, rituals, temper tantrums, and obsessive compulsive tendencies may all prevent a normal family life (Higgins et al., 2005; Pilowsky, Yirmiya, Doppelt, Gross-Tsur & Shalev, 2004).

The lack of acceptance of autistic behaviors by society and family members is a contributing factor of stress as well (Sharpley et al., 1997). Many parents report that handling family and friends on a daily basis is extremely stressful due to others' lack of knowledge and understanding of the disorder (Jones & Passey, 2005). In fact, research has shown that a chronic psychological disorder may entail more stress on the family than a chronic physical illness, such as cystic fibrosis (Bouma & Schweitzer, 1990). This could possibly be a result of societal attitudes toward mental illness and the stigma that is attached. The stress on families with a child with Autism may be exacerbated because the disorder is generally not identifiable by physical appearance (Higgins et al., 2005). Because the child appears quite typical, when the child misbehaves, parents are faced with criticism for their poor parenting skills instead of sympathy for the challenging behaviors they must control (Manning-Courtney et al., 2003). Consequently, people are often insensitive regarding the public behavior of children with Autism, which may lead to increased stress in the caregivers.

Low levels of support provided by health care and social services are another major factor of stress associated with raising a child with Autism. Families are often forced to face a lack of appropriate local services, a lack of sufficient special education facilities, and limited knowledge of problems associated with the disorder (Sivberg, 2002). Stress also results from issues regarding the child's educational placements, such as mainstreaming, and a lack of information about coping and managing the daily life of

children or adolescents with Autism (Dyson, 1997). In addition, caregivers tend not to utilize formal support services to a degree that is consistent with their level of need (Kazak & Marvin, 1984). This is of particular importance because the literature suggests that professional support services constitute a substantial difference in the caregivers' perceptions of stress (Weiss, 2002). In fact, the mere perception of support appears to curb the extent to which parenting stress leads to distress. The combination of a lack of sufficient professional support and not taking advantage of the support that is available results in a reliance on informal sources of support within the family, further increasing the stress on caregivers and the family.

In addition to the factors stated above, other aspects of raising a child with Autism significantly contribute to stress. Certain features of the child's disability, including level of functioning, severity, and child characteristics play a role in the amount of stress the family experiences (Perry et al., 2005). Parents of children with lower levels of adaptive functioning and more maladaptive behaviors display higher levels of family problems, parental pessimism, and parental distress compared to parents of children with higher levels of adaptive functioning (Bouma & Schweitzer, 1990). For instance, there is a significant correlation between the child's deviation in temperament, unresponsiveness, repetitive behaviors, and demandingness and the amount of stress reported by mothers (Bouma & Schweitzer, 1990).

Because many children with Autism have an additional diagnosis of Mental Retardation, the child's degree of cognitive ability may also significantly influence the amount of stress experienced by the family members (Weiss, 2002). Determining a child's true intellectual ability and skills is often difficult and leads to confusion

regarding his or her cognitive abilities and potential, which may lead to additional stress due to the unknown nature of abilities. Another factor of stress is social disability, which is a characteristic of the disorder that results in deficits in emotional expressiveness (Bouma & Schweitzer, 1990). Children with Autism are often aloof or avoidant of attempts at affection (Weiss, 2002), which may result in diminished empathy between the caregiver and the child (Bouma & Schweitzer, 1990). These factors, or a combination of these factors, play a contributing role in the stress experienced by the caregiver.

Effect of Stress

Due to the difficulties of raising a child with a disability, parents of children with Autism report more stress than parents of typically developing children (Erguner-Tekinalp & Akkok, 2004). They often face atypical caregiving challenges that may increase the likelihood of physical and mental health consequences (Seltzer, Greenberg, Floyd & Hong, 2004). Research has indicated that fatigue, lowered self-esteem, interpersonal dissatisfaction, helplessness, feelings of inadequacy and failure, anger, shock, guilt, frustration, and resentment may be experienced by these caregivers (Weiss, 2002). There is extensive literature indicating that the stress on families with children with Autism is even higher than in families of children with other disabilities (e.g., Weiss, 2002). For example, parents of children with Autism report more parenting stress than parents of children with Down Syndrome, which is a chronic condition often compared to Autism in the literature (Hastings et al., 2005). In fact, Holroyd and McArthur (1976) found that mothers of children with Autism were more distressed about their child's dependency, the effect of their child on the rest of the family, and vocational handicaps when compared to mothers of children with Down Syndrome. Increased stress

in parents of children with Autism has also been found when compared to parents of children with Mental Retardation, cystic fibrosis, children seen on a psychiatric outpatient unit, and children with other developmental disabilities (Perry et al., 2005; Weiss, 2002).

Research indicates that mothers of children with Autism are particularly vulnerable to the effects of stress (Gray & Holden, 1992). According to Weiss (2002), mothers of children with Autism indicate the highest amount of depressive symptomatology when compared to mothers of children with Mental Retardation and mothers of typically developing children. Additionally, increased moodiness, vulnerability to illness, inability to pursue personal goals, having little free time, and experiencing frustration over the amount of time devoted to the child with Autism are also reported. Although all mothers of children with Autism are vulnerable to the effects of stress, it remains unclear why some mothers feel more overburdened than others (Duarte et al., 2005). Research indicates that certain personality and demographic factors of the mother may be associated with higher stress levels. A mother with limited expression of affection, low interest in others, and being an older mother with a younger child are factors that, when considered together, contribute to higher levels of stress (Duarte et al., 2005).

Because the existing literature focuses primarily on mothers of children with Autism, there is little information regarding the consequences of stress on fathers. Nonetheless, in a study conducted by Dyson (1997), fathers of school-age children with disabilities reported as much stress as mothers and significantly greater amounts of parental stress than fathers of school-age children without disabilities. Thus, results from

this study suggest parallel family experiences for fathers and mothers when raising a child with a disability.

A growing body of literature suggests that chronic disability in a family member not only negatively impacts the parents, but family functioning as well (Higgins et al., 2005). Caring for a child with Autism may represent a source of stress on the entire family unit in addition to relationships among family members. Studies of families with a disabled child show less supportive family relationships, fewer opportunities to pursue personal activities, and more rigid households (Margalit, Raviv & Ankonina, 1992). In families with a child with Autism, disruption in the quality of family life, marital discord, and social isolation have been reported as well, indicating more negative consequences of stress in these families (Dumas, Wolf, Fisman & Culligan, 1991).

Siblings are also affected by the stress related to the presence of a child with Autism in the family. They may be forced to cope with a variety of issues, such as changes in family roles, structure and activities, feelings of guilt and shame, loss of parental attention, and increased stress in the family (Pilowsky et al., 2004). Existing literature regarding the effects of having a sibling with Autism have been inconsistent (Rivers & Stoneman, 2003). A number of authors have indicated that there can be both positive and negative effects on the sibling (e.g., Bagenholm & Gillberg, 1991; Fisman, Wolf, Ellison & Freeman, 2000; Pilowsky et al., 2004), whereas other authors indicate no differences between siblings of children with Autism and controls (Rivers & Stoneman, 2003).

Because Autism impacts more areas of functioning in the child than many other disabilities, siblings of children with Autism may experience higher levels of stress (Fisman et al., 2000; Pilowsky et al., 2004). This stress may lead to negative effects, such as chronic emotional and behavioral problems in the non-disabled child. Some studies indicate that siblings have an increased risk of developing psychosocial problems and high levels of externalizing and internalizing problems (Bagenholm & Gillberg, 1991; Fisman et al., 2000). For instance, previous research has found increased maladjustment, anxiety, social dysfunctions, isolation, behavior problems, depression, and loneliness in siblings of children with Autism (Pilowsky et al., 2004; Rivers & Stoneman, 2003).

On the other hand, some researchers have reported positive findings in siblings (Rivers & Stoneman, 2003). Research has indicated that some siblings report greater warmth in their relationship as a result of the ability to “teach” their sibling with Autism and act as important social agents for them. Additionally, siblings of children with Autism have been found to be well-adjusted with a positive self-concept compared to siblings with other disabilities or with normal development (Pilowsky et al., 2004). Nonetheless, some existing literature has found no differences between sibling groups in behavior problems, self-esteem, or social competence (Rivers and Stoneman, 2003).

Regardless of the inconsistency in literature on the consequences of stress on siblings, they are forced to cope with a complicated family system due to the presence of a child with Autism within the family. Thus, both siblings and caregivers are vulnerable to the psychological and physical effects of increased stress (Seltzer et al., 2004; Weiss, 2002). In order to manage this intense stressor, effective methods of coping must be utilized.

Coping

Living with a child with Autism requires coping strategies in order to successfully adapt to a stressful situation. Coping has been defined as “cognitions and behaviors used by the individual in evaluating stressors and in initiating activities with the aim of decreasing their impact” (Margalit et al., 1992). There have been surprisingly few studies in the literature on the types of coping strategies used by parents of children with Autism (Hastings et al., 2005). In order to successfully adapt, it is important that parents develop and employ as many effective coping strategies as possible (Sivberg, 2002). Coping may be context-dependent, meaning that the nature of the stress and the interaction of stressors and the environment affect the development of coping (Hastings et al., 2005). Therefore, coping strategies vary from one family to the next and even between mothers and fathers within the same family. Research suggests that coping in parents of children with Autism may also be different to that of parents of children with other conditions. In families with a child with Autism, coping is essential for the maintenance of the family and the quality of life for each family member (Erguner-Tekinalp & Akkok, 2004).

According to Endler and Parker (1990b), people cope with stress in three main ways: (1) task-oriented coping (i.e., strategies that attempt to solve a problem, reconceptualize a problem, or minimize the effects of a problem), (2) emotion-oriented coping (i.e., emotional responses, self-preoccupation, and fantasizing reactions), and (3) avoidance-oriented coping (i.e., strategies that involve avoiding a stressful situation by seeking out others or those that involve engaging in a substitute task). Task-oriented coping has been found to be related to adaptation, whereas emotion-oriented coping has been associated with psychological distress and mental health problems (Endler, Parker

& Butcher, 1993). Avoidance-oriented coping has been found to be unrelated to psychopathology.

Previous studies examining the coping strategies of parents of children with Autism have used coping measures that describe avoidant coping much like emotion-oriented coping (Hastings et al., 2005; Margalit et al., 1992). Additionally, the social support component of avoidance-oriented coping that is included in Endler and Parker's (1990b) scale has not been measured in avoidant coping in past research. Therefore, there is some confusion in the literature regarding the measurement of avoidance-oriented coping. As it is traditionally used in past research, parents of children with disabilities exhibit all types of coping methods, but have been shown to use a greater amount of avoidant coping (Margalit et al., 1992). The severity of problems by the disabled child are related to the parents' increased use of avoidant coping. For instance, parents whose children display more disruptive behavior seem to use more avoidant coping. The increased use of avoidant coping may be a function of their inability to change the source of stress (i.e., the child's disability), as well as their need for varied coping mechanisms to manage the increased demands of the child. Therefore, parents of children with Autism may use more avoidant coping methods than parents of children with other disabilities due to the severity of the disorder

An important factor in reducing stress and coping effectively is social support. Whereas social isolation is associated with psychopathology, social support is a protective factor that can aid in coping with the stress of caring for a child with Autism (Kazak, 1992; Seltzer et al., 2004). In general, the larger the social network, the greater the likelihood of successful adaptation (Kazak, 1992). Because social support is

associated with parental symptomatology and feelings of adequacy in parenting (Weiss, 2002), increased availability of support results in better adaptation. Informal social support networks appear to be even more critical than formal support. One of the most frequent sources of support for parents is the family, including support from spouses, relatives, and partners (Jones & Passey, 2005; Weiss, 2002). Coping strategies involving family integration and optimism are strongly associated with decreased stress relating to overall family cohesiveness, the parent's perceptions of satisfaction in caring for their child, and their concerns over future care of their child (Jones & Passey, 2005). As indicated earlier, this may occur in part because of the lack of formal support available and the tendency for families with children with Autism not to utilize formal support networks.

The model of coping frequently referenced in the literature as a way of understanding the parental stress in families with children with Autism is the ABC-X model of stress and coping (Jones & Passey, 2005). The original ABC-X model is composed of "A", which represents the stressor (i.e., child with Autism) and is defined as "a life event or transition impacting upon the family unit which produces, or has the potential of producing, change in the family social system". "A" interacts with "B", which represents the family's resources and ability to prevent a crisis in the family system. "B" interacts with "C", which represents the family's definition or seriousness of the stressor. The combination of these factors produce "X", which represents the crisis and denotes the amount of disruptiveness, disorganization, or debilitation in the family system (McCubbin & Patterson, 1983). If the family is able to use its resources and

define the stressor in a manner which resists change and maintains stability within the family, then the stress may never reach the crisis stage.

Based on the original ABC-X model of coping, the Double ABC-X model was created in order to simultaneously address psychological, intra-familial, and social variables from previous family stress (Jones & Passey, 2005). Developed by McCubbin and Patterson (1983), this model indicates that a parent's ability to cope with a stressful situation is determined by the interaction of the stressor event and subsequent life stressors, family resources, parental perceptions, and coping strategies. In this model, the "aA" factor describes a pile-up of stressors and strains, which may stem from individual family members, the family system, or the community. The family's adaptive resources, including existing resources and expanded family resources, comprise the "bB" factor of this model. Existing resources are defined as resources within the family which minimize stress, whereas expanded family resources are new resources which are strengthened or developed in response to the stress. The "cC" factor indicates the family's meaning of the crisis and includes the stressor which caused the crisis, additional stressors, resources, and resolutions. Finally, the "xX" factor is the amount of crisis in the family system, as well as the family's adaptation to the crisis. The result of this interaction is the level of family adaptation ranging from severe stress to successful adjustment (Jones & Passey, 2005). Many previous studies have used this model to examine parental stress of a child with a developmental disability, such as Autism.

Jones and Passey (2005) utilized the Double ABC-X model of coping to explore parental stress in families with children with developmental disabilities and behavior problems. In this study, an assessment of child and parent characteristics, including the

child's gender, age, disability, and behavior difficulties was administered to determine the "aA" factor in the model. To establish the "bB" factor, the availability, type, and helpfulness of family resources and subsequent coping styles was measured using the Family Support Scale and the Coping Health Inventory for Parents. The Parental Locus of Control was administered to determine parental perceptions of stressors in order to determine the family's meaning of the crisis, or the "cC" factor of the model. Lastly, the "xX" factor was established using the Questionnaire on Resources and Stress by assessing family adaptation and the level of distress within the family (Jones & Passey, 2005).

This model of coping served as a framework in the interpretation of parental stress in families with a developmentally disabled child. Results showed the importance of coping strategies and perceptions in influencing the amount of stress experienced by the parents (Jones & Passey, 2005). For example, the use of active coping strategies, social support networks, and parental perceptions of adequacy in parenting appear to reduce stress. The results of this study help explain the interaction of the stressor, family adaptation, and successful coping strategies. The Double ABC-X model will also be applied in the present study to examine stress and coping within families of children with Autism. It will be used as a tool in designing the study, particularly in determining the measures to be employed.

The Double ABC-X model of coping illustrates the variability of outcome in families coping with the stress of raising a child with Autism. Family outcomes can vary from healthy adaptation to maladaptation (Jones & Passey, 2005). Existing literature indicates tremendous heterogeneity among families with children with Autism, with

some families coping effectively, while others reporting significant distress (Perry, 2005). Recent research implies that although some families are at risk for significant stress and strain, many families can positively cope and adapt to the stress of caring for a child with Autism (Jones & Passey, 2005). One factor that may account for the variability of coping outcomes is the type of parenting style used by the caregivers.

Parenting Style

The style of parenting employed by the caregiver may be a coping strategy utilized to deal with increased stress, and may also play a role in determining why some caregivers feel more overwhelmed than others in the task of raising a child with Autism. According to Baumrind (1966), parenting style is a term used to describe an overarching construct that groups of parents differ in specific behaviors, such as the way they use control, as well as other dimensions. Baumrind purposed three models of parental control: (1) permissive, (2) authoritarian, and (3) authoritative, each with its own set of beliefs and behaviors.

The permissive parent is non-punitive, accepting and affirmative toward the child's impulses, desires, and wishes. The child is consulted regarding family rules and the parent gives explanations to the child for these rules. Few demands for household responsibility are placed upon the child. The permissive parent is a resource for the child to use as he or she wishes, rather than a model for the child to imitate. The parent is not seen as being responsible for shaping or altering the child's behavior. For example, the parent allows the child to monitor his or her own activities, avoids control of the child, and does not encourage the child to obey rules or regulations. The permissive parent attempts to use reason and manipulation rather than overt power (Baumrind, 1966).

The authoritarian parent attempts to shape, control, and evaluate the child's behavior and attitudes in accordance with a set standard of conduct. The parent believes in restricting the autonomy of the child. For example, the parent uses punitive and often forceful measures when the child's actions conflict with the parent's beliefs. Obedience is a highly valued virtue of the authoritarian parent. For instance, verbal give and take is not encouraged of the child because the parent believes that the child should accept his or her word for what is right. The preservation of order and structure is also highly valued (Baumrind, 1966).

The last method of parental control is the authoritative parent. Autonomous self-will and disciplined conformity are highly valued. The parent uses reason, power, and reinforcement to achieve his or her objectives and does not base decisions on the individual child's desires. When disagreement occurs between the parent and the child, the parent uses firm control but does not restrict the child. The parent attempts to direct the child's activities in a rational manner and sets standards for future conduct. For example, the parent encourages verbal give and take and explains the reasoning behind rules (Baumrind, 1966).

Another characteristic of the authoritative parent is responsiveness, as indicated by Maccoby and Martin (1983) who built upon Baumrind's approach to parental control. Responsiveness can be described as responding to the child's behavior or "as parental sensitivity and adaptation to the child's signals, states, and needs..." (Seipp & Johnston, 2005). The construct of responsiveness contains variables such as parental approval of the child, affection, synchrony of communication, and non-forceful control of the child (Johnston, Murray, Hinshaw, Pelham & Hoza, 2002; Seipp & Johnston, 2005). Previous

research indicates a negative correlation between maternal responsiveness and child conduct problems (Johnston et al., 2002). In addition, it is also negatively related to maternal depressive symptoms (Johnston et al., 2002).

Because of its influence on parental stress and symptomatology, the style of parenting employed by caregivers with a child with Autism may be an essential mechanism of coping. Research indicates that the way a caregiver parents influences child outcomes (Onatsu-Arvilommi, Nurmi & Aunola, 1998), which in turn is related to the amount of stress and symptomatology the caregiver experiences (Baker et al., 2003). For example, a highly stressed parent may use parenting techniques that are related to the introduction or exacerbation of child behavior problems, which cause increased stress in the parent and possible symptoms of psychopathology. Although parenting behavior has been shown to be a factor in coping and adaptation in parents of children with developmental disabilities (Beresford, 1994), there is little research on the relationship between parenting behavior and parenting stress (Hastings & Beck, 2004). Further, the parenting styles utilized by caregivers of children with Autism have yet to be explored. However, the parenting styles employed by parents of children with other chronic conditions, such as attention deficit/hyperactivity disorder (ADHD), have been examined. Because of the behavioral difficulties and permanency associated with the disorder, the parenting style associated with children with ADHD can be compared to that of children with Autism. ADHD is even more relevant than conditions that are typically compared to Autism, such as Down Syndrome, because of the behavioral problems common to both disorders. It must be noted, however, that this is a limited comparison because Mental Retardation is not strongly associated with ADHD as it is with Autism. Nonetheless, the

comparison between these two groups fits with the “daily hassles” conceptualization of stress that is being used in the current study.

ADHD is characterized by developmentally inappropriate levels of inattention, impulsivity, and motor activity (American Psychiatric Disorder, 2000). Recent studies suggest that families of children with ADHD usually possess greater parent-child interaction difficulties than controls (Johnson et al., 2002; Seipp & Johnston, 2005). Therefore, parenting style has a significant effect on the expression of core ADHD behavioral symptoms, such as inattentiveness, hyperactivity, and impulsivity (Monastra, Monastra & George, 2002).

Higher levels of authoritarian parenting methods have been reported by parents of children with ADHD compared to parents of emotionally disordered children or controls (Lange et al., 2005). For example, parents use more commands, negative statements, and less praise with their children (Johnston et al., 2002). Some existing research supports a link between an unresponsive style of parenting and ADHD child behaviors, which could account for the increased problems between the parent and the child (Monastra et al., 2002). Parents may have particular difficulty using a responsive parenting style because of the child’s disorganized and poorly regulated behavior. Parents coping with multiple family stresses with limited social support and a diminished quality of life may also be less tolerant of children with ADHD (Lange et al., 2005). Consequently, parents who are less tolerant of these children may engage in parenting styles and patterns of family functioning which exacerbate ADHD symptoms rather than alleviate them. Similarly, parents of children with Autism may exhibit parenting behaviors that affect child outcomes (Hastings & Beck, 2004). A study conducted by Baker et al. (2003) found

changes in child behavior problems to be associated with increases in parental stress. However, changes in parenting stress were also related to child behavior problems, indicating a bidirectional effect. In other words, parenting style interacts with child characteristics and vice versa. Because of its bidirectional effect, however, limitations exist when examining parenting style as a coping strategy.

Parenting a child with a chronic condition not only affects the child, but the parental experience as well. Parents of other disabled children report less satisfaction, lower self-esteem, and less competence in the parenting role than controls (Johnston, 1996; Seipp & Johnston, 2005). Thus, it is reasonable to hypothesize that parents of children with Autism would as well. Consistent with this, mothers of children with Autism express less competence as parents and find parenting less rewarding (Fisman et al., 2000). Additionally, dissatisfaction in parenting may also have an impact on the siblings of these children; however, this has yet to be explored.

Summary

Raising a child with a severe developmental disability like Autism creates significant distress in the lives of the caregivers, siblings, and on the family as a whole (Higgins et al., 2005; Sanders & Morgan, 1997). Because Autism impacts many critical areas of functioning in the child, research indicates that parents of children with Autism experience greater stress than parents of typically developing children (Erguner-Tekinalp & Akkok, 2004), parents of children with Down Syndrome (Hastings et al., 2005), and parents of children with other disabling conditions (Perry et al., 2005; Weiss, 2002). Sharpley et al. (1997) also indicate higher amounts of stress due to the permanency of the condition, the lack of acceptance of behaviors by society and family members, and low

levels of support. Other factors that are characteristic of the disorder, such as temperament, unresponsiveness, repetitive behaviors, and Mental Retardation, also play a role in the stress placed upon the family (Bouma & Schweitzer, 1990; Weiss, 2002). In the present study, stress is conceptualized according to the "daily hassles" paradigm, which suggests that everyday annoyances and hassles are the key source of stress within the family. The administration of the QRS-F will aid in conceptualizing stress according to this model.

The stress associated with raising a child with Autism may result in physical and mental health consequences, such as fatigue, depression, interpersonal dissatisfaction, helplessness, and feelings of inadequacy (Seltzer et al., 2004; Weiss, 2002). Furthermore, siblings of children with Autism also undergo increased amounts of stress resulting from a complicated family system, such as changes in family roles, structures, and activities, loss of parental attention, and feelings of guilt and shame (Pilowsky et al., 2004). However, research also indicates positive consequences in children with a sibling with Autism (Pilowsky et al., 2004); therefore, research has been inconsistent (Rivers & Stoneman, 2003).

In order to manage the stress and ensuing physical and mental health consequences related to living with a child with Autism, effective coping strategies must be employed. Although there is little research on the types of coping used by parents of children with Autism, task-oriented coping and social support appear to be mechanisms of coping associated with successful adaptation (Hastings et al., 2005; Jones & Passey, 2005; Seltzer et al., 2004). In the present study, the Double ABC-X model of coping will

be used as a framework in the interpretation of parental stress and coping to illustrate the variability of outcomes in families.

One type of coping strategy that the present study seeks to explore is the parenting style utilized by the caregivers of children with Autism. Baumrind's (1966) identification of three parenting styles (permissive, authoritarian, and authoritative) will be examined in these parents through the use of the Parental Authority Questionnaire—Revised (PAQ-R). Because previous research has not yet investigated the styles of parenting utilized by caregivers of children with Autism, it is necessary to explore this area to find if one parenting style is more effective than another. Based on the literature of parents with children with ADHD, parenting style may have a significant effect on the expression of characteristics associated with the disorder (Monastra et al., 2002). Thus, parenting style may be an effective coping strategy utilized by the caregivers to reduce the degree of autistic symptoms, which consequently may decrease parental stress and symptomatology, resulting in successful adaptation of the stressor.

Present Study

The present study is designed to broaden the knowledge of successfully coping with the stress associated with raising a child with Autism by examining parenting style and how it is related to stress and symptomatology in the caregiver. Additionally, differences in parenting in the child with Autism versus the non-affected sibling will be explored. First, the severity of autistic symptoms will be examined for its effect on parental symptomatology and stress. Second, parenting style and methods of coping will be measured to determine its effect on coping with the stress of raising a child with Autism. Lastly, this study will focus on parents of children with Autism with at least one

sibling. Because little research has been conducted on the parenting differences between siblings, this focus is of extreme importance in determining how caregivers may use parenting style as a coping mechanism.

Based on the information attained in the literature review, the following questions and hypotheses have been generated for the present study:

Q1. Will the severity of Autism in the child relate to parent symptomatology?

H1. As the severity of autistic symptoms increases, parental symptomatology increases as well.

Q2. Will the severity of Autism in the child relate to the level of familial stress?

H1. As the severity of autistic symptoms increases, familial stress as perceived by the parent increases as well.

Q3. Are there mediating variables in coping with the stress of raising a child with Autism?

H1. The severity of autistic symptoms in the child will be related to the parenting style.

H2. As the use of an authoritative parenting style for the child with Autism increases, familial stress as perceived by the parent decreases.

H3. As the use of task-oriented coping increases, familial stress as perceived by the parent decreases.

Q4. Are there differences in parenting style between the child with Autism and the identified sibling?

H1. Parents use different styles of parenting for the children with Autism compared to the identified siblings.

Because some research in this area remains exploratory, additional questions will be considered.

CHAPTER II

METHOD

Participants

The participants consisted of 81 primary caregivers (71 mothers, 4 fathers, 3 grandparents, and 2 other) of a child with Autism. Participants were recruited from parental support groups via electronic list-serves throughout Ohio, Indiana, and Kentucky. One hundred and fifty questionnaire packets were mailed and 81 were returned, yielding a 54% return rate. Four packets were returned after the deadline for analysis and so were not included in the study.

Information regarding the mother and father of the child with Autism was gathered. The mothers' mean age was 39.99 years and the fathers' mean age was 42.30 years. With respect to education level, the majority of the mothers reported completing college (70.9%), with 26.6% also having an advanced degree, 16.5% completing some college, and 12.7% having a high school diploma. Most fathers reported having a college degree (69.4%), with 19.4% having an additional advanced degree, 13.9% completing some college, and 16.7% having a high school diploma. The majority of parents were married (80%), and the remaining participants reported being divorced (13.8%), single (5%), or widowed (1.3%). The annual income of the families varied, with 6.5% with an income of less than 20,000 per year, 19.5% making 20,000-39,999 a year, 20.8% making

40,000-59,999, 20.8% with an income between 60,000 and 79,999, 7.8% making 80,000-99,999, 18.2% making between 100,000 and 149,999, and 6.5% making over 150,000 per year. When inquired about the use of support systems, 95.1% of participants reported employing at least one type of support. Using a spouse as a source of support was endorsed by 77.9% of respondents, 77.9% use health services (e.g., speech therapy), 74% reported using family as a source of support, 71.4% use educational services (e.g., tutoring), 66.2% use friends as support systems, 66.2% participate in a local support group, 61% use an internet support group or list-serve, 48.1% use social services (e.g., financial support), 40.3% use mental health services (e.g., individual or group therapy), and 40.3% reported using other types of support systems (e.g., church). Participants were asked to rate their satisfaction (*1 = not at all satisfied to 5 = extremely satisfied*) of the support systems used and the average rating for informal support systems (family and friends) was 3.94 (SD = .90) and 3.96 (SD = .78) for formal support systems.

Information was also collected about the child with Autism. Children diagnosed with Autism comprised 48.8%, and the remaining diagnoses included Autism Spectrum Disorders (21.3%), Asperger's Syndrome (15%), and Pervasive Developmental Disorder-Not Otherwise Specified (15%). The mean age at diagnosis was 3.75 years. In making these diagnoses, 40.5% of children were diagnosed by a psychologist, 29.1% were diagnosed by a psychiatrist, 12.7% were diagnosed through a multi-team approach (i.e., professionals from several fields), 3.8% of children were diagnosed by a pediatrician, and 13.9% of diagnoses were made by other professionals (e.g., neurologist). The majority of the children with Autism were male (88.9%), whereas 11.1% were female. Ages ranged from two to 22, with a mean age of 8.43 years. With regards to the identified siblings,

50.8% were male and 49.2% were female. Ages ranged from one to 20, with a mean age of 8.21 years.

Measures

Demographic Information

A demographic sheet was administered which asked participants his or her relationship to the child with Autism, the age and level of education of the parents, marital status, yearly income, formal diagnosis of the child, the type of professional who diagnosed the child, the age of the child at diagnosis, the age and gender of the child with Autism and the identified sibling, the age and gender of other siblings, and types of support systems, including length of use and level of satisfaction of each (see Appendix B).

Severity of Autistic Symptoms and Stress

The present study used the Childhood Autism Rating Scale—Parent Version (CARS-P; Schopler, Reichler & Renner, 1988) to assess the degree of autistic symptoms and corresponding stress levels (see Appendix C). The CARS-P consists of 14 items and severity is rated on a 4-point scale ranging from 1 (“normal for chronological age”) to 4 (“severely abnormal for chronological age”) (Tobing & Glenwick, 2002). The following item domains are included: (1) relating to people, (2) imitation, (3) emotional response, (4) body use, (5) object use, (6) adaptation to change, (7) visual response, (8) listening response, (9) taste, smell, and touch response and use, (10) fear or nervousness, (11) verbal communication, (12) nonverbal communication, (13) activity level, and (14) level of consistency of intellectual response. Each item of the CARS-P specifies a symptom and a brief description, for example, “difficulty with change in the environment (e.g.,

new living room furniture)". The total score of the ratings can be used to make one of three classifications: no Autism (15-30 points), mild to moderate Autism (30-36 points), or severe Autism (36-60 points) (Schopler, Reichler, DeVellis & Daly, 1980). For the purpose of this study, all children have been identified with Autism; however, this measure will be useful in classifying children as mildly or severely autistic. Thus, the use of the CARS-P in the present study differs slightly than its initial design in that it is not being used as a diagnostic tool. Parents also rate the stressfulness of each domain on a 4-point scale ranging from 1 ("none at all") to 4 ("extreme") (Tobing & Glenwick, 2002).

The CARS-P was developed from the CARS, which was originally designed for use by professionals to identify children with Autism according to commonly employed criteria (Tobing & Glenwick, 2002). Bebko et al. (1987) wanted to study which individual symptoms of Autism parents find most stressful, as well as assess the accuracy in estimating parental levels of stress by professionals. Consequently, the CARS-P was developed to obtain parents' perspectives of their child's level of functioning (Tobing & Glenwick, 2002). This self-report measure is of interest because it reflects parental perceptions of the child and represents the child's family life. For example, parents' impressions of their child's level of disability may influence the ways in which they interact with their child and further impact the family system.

Based on over a decade of use with more than 1,500 children, the CARS has shown to be an extremely reliable and valid assessment tool (Schopler et al., 1988). Internal consistency, interrater reliability, and test-retest reliability have been demonstrated to be .94, .71, and .88, respectively. Additionally, criterion-related validity and validity of the CARS ratings made under alternate conditions and by professionals of

other disciplines were shown to be above average. In regards to the CARS-P, parent reported severity and stress scores have been found to be strongly correlated with scores given by professionals. Furthermore, adequate agreement between mothers' and fathers' ratings has been found (Bebko et al., 1987). The relationship between CARS-P severity and stress ratings has also been investigated and it has been found that overall severity scores by both mothers and fathers were associated with the total stress score. In addition, the domains classified as most severe by parents received the highest stress ratings. These findings generally support the use of the CARS-P as a means to assess parental perceptions of the functioning of their child with Autism (Tobing & Glenwick, 2002).

Stress

In order to measure the level of familial stress as reported by the parent, the Questionnaire on Resources and Stress—Friedrich Short Form (QRS-F; Friedrich, Greenberg & Crnic, 1983) was administered (see Appendix D). This measure consists of 52 self-administered, true-false items measuring parental perception of the impact of a developmentally delayed, handicapped, or chronically ill child on the family, as well as the family's emotional response. Items representing coping difficulties in the family and degree of handicap or dependency in the family member are included in the measure. The Friedrich Short Form of the QRS was developed to be a shorter and psychometrically stronger version of the original QRS (Friedrich et al., 1983) and is the most widely used short form (Honey, Hastings & McConachie, 2005).

Parental perception is measured among the following four factors: (1) parent and family problems, (2) pessimism, (3) child characteristics, and (4) physical incapacitation. The first factor, parent and family problems, is comprised of 20 items that measure the

parents' perception of stress for themselves, other family members, or the family as a whole due to the impact of the handicapped child. The original QRS scales included in this factor are poor health/mood, excess time demands, lack of family integration, and limits on family opportunity (Friedrich et al., 1983). Sample items include "our family agrees on important matters" and "I can go visit with friends whenever I want."

Pessimism, the second factor, consists of 11 items addressing the child's ability to achieve self-sufficiency. Negative attitude toward index case, overprotection/dependency, overcommitment, pessimism, and lack of activities for index case are the domains included from the original QRS. Sample items include "I am disappointed that _____ does not lead a normal life" and "time drags for _____, especially free time." The third factor is comprised of 15 items from the QRS scales of difficult personality characteristics, negative attitude toward index case, and occupational limitations for index case. Parental perceptions of behavioral and attitudinal differences of the child are included in this scale. Examples of items include "Sometimes I avoid taking _____ out in public" and "_____ knows his/her own address." Physical incapacitation, the fourth factor, contains 6 items that assess the degree in which the handicapped child can perform activities. Sample items include "_____ can feed himself/herself" and "_____ is able to go to the bathroom alone." Scores for each factor, as well as a total score, can be calculated.

The QRS-F and the QRS have been shown to be closely related as evidenced by a correlation of .997 between the two measures (Friedrich et al., 1983). The QRS-F has also demonstrated good reliability and validity. Alpha reliability coefficients range from .77 to .93, which yields internally consistent scores for the four factors (Honey et al.,

2005; Scott, Thompson & Sexton, 1989). The Kuder Richardson-20 reliability coefficient ranges from .93 to .95, which is a highly accepted value (Friedrich et al., 1983). In criterion validity studies, the QRS-F has been demonstrated to be useful in distinguishing between populations that differ in diagnosis, degree of handicap, family characteristics, family stress, parent attributes, and if the child lives at home (Holroyd, 1988). This is also known as validity generalization, which suggests that the QRS-F can be helpful in a wide range of situations and samples. For example, previous studies have shown the QRS-F to differentiate between parents of children with Autism, children with Down Syndrome, or children who were psychiatric outpatients (Friedrich et al., 1983).

Coping Styles

In order to assess for the coping style utilized by the parent of the child with Autism, the Coping Inventory for Stressful Situations (CISS; Endler & Parker, 1990b) was employed (see Appendix E). It is comprised of three scales that measure task-oriented (T), emotion-oriented (E), and avoidance-oriented (A) coping styles. The avoidance scale contains two subscales: distraction (D) and social diversion (S). An example of a task-oriented item includes "schedule my time better", whereas emotion-oriented coping includes items such as "blame myself for procrastinating" and "become preoccupied with aches and pains." The distraction subscale of avoidance-oriented coping includes items such as "window shop" and the social diversion subscale is comprised of items like "try to be with other people." Each scale consists of 16 items, yielding a 48 item instrument. Participants respond to items based on the frequency of behaviors during a stressful situation. Responses range from 1 ("not at all") to 5 ("very much"). The total score for each scale range from 16 to 80, and raw scores can be

converted to standard scores and percentiles using the profile sheet. The standard score is the T-score, which has a mean of 50 and a standard deviation of 10 for all scales.

Norms for the CISS were founded on several samples, including 537 adults, 1,242 undergraduates, 302 psychiatric inpatients, 313 adolescents (13-15-years-old), and 504 adolescents (16-18-years-old). Separate means and standard deviations from the normative sample were calculated for males and females. Based on the samples, reliability for the CISS has demonstrated to be generally high, with slightly lower alpha coefficients for the psychiatric inpatient sample. For the task scale, alpha ranged from .87 to .92. Alpha ranged from .82 to .90 on the emotion scale and .76 to .85 for the avoidance scale. Both subscales of the avoidance scale demonstrated good internal reliability. Alpha ranged from .69 to .79 for the distraction subscale and .74 to .84 for the social diversion subscale. Using 238 undergraduates after a 6-week period yielded good test-retest correlations reliability for the CISS as well. Both task and emotion scales had a correlation value equal to or greater than .68 for males and females. Reliability correlations for the avoidance scale and its two subscales ranged from .51 to .61. The CISS has also demonstrated adequate construct validity. Emotion-oriented coping is highly related to distress and psychopathology, whereas Task-oriented coping and avoidance-oriented coping are not.

Parent Symptomatology

The present study used the Symptom Checklist-90-Revised (SCL-90-R; Derogatis, 1994) to examine a broad range of psychological problems and symptoms of psychopathology in the parent of the child with Autism (see Appendix F). This instrument is designed to provide an overview of a patient's symptoms and their intensity

with a time reference of "the past 7 days including today". It is a 90-item self-report questionnaire comprised of 9 primary symptom dimensions and 3 global indices. The primary symptom dimensions include: (1) Somatization (SOM), (2) Obsessive-Compulsive (O-C), (3) Interpersonal Sensitivity (I-S), (4) Depression (DEP), (5) Anxiety (ANX), (6) Hostility (HOS), (7) Phobic Anxiety (PHOB), (8) Paranoid Ideation (PAR), and (9) Psychoticism (PSY). A sample of items includes "poor appetite", "worrying too much about things" and "nausea or upset stomach." Included in the 3 global indices are: (1) the Global Severity Index (GSI), which is designed to measure overall psychological distress, (2) the Positive Symptom Total (PST), which reports the number of self-reported symptoms, and (3) the Positive Symptom Distress Index (PSDI), which measures the intensity of symptoms. Symptoms are rated on a 5-point Likert scale, ranging from 0 ("not at all distressing") to 4 ("extremely distressing"). Subscale scores are calculated by summing item scores for the entire instrument and dividing by the total number of items on each subscale. The GSI is found by summing the scores for the 90 items and dividing by 90. The PST score is found by adding all items not scored zero and the PSDI is found by dividing the grand total by the PST score.

SCL-90-R norms were established using samples from four groups that included 1,002 adult psychiatric outpatients, 974 adult non-patients, 423 adult psychiatric inpatients, and 806 adolescent non-patients. Over 1,000 studies have been conducted demonstrating the reliability, validity, and utility of the SCL-90-R. Research indicated good internal reliability with an alpha range of .77 for psychoticism to .90 for depression. Test-retest reliability coefficients ranged between .80 and .90 after one week of therapy. The SCL-90-R has also been demonstrated to have levels of concurrent,

convergent, discriminant, and construct validity comparable to other self-report inventories.

Parenting Style

The Parental Authority Questionnaire—Revised (PAQ-R; Reitman, Rhode, Hupp & Altobello, 2002) was administered to determine the style of parenting used by the parent of the child with Autism and the identified sibling (see Appendix G). The original PAQ is a 30-item questionnaire based on descriptions of Baumrind's (1966) proposed prototypes of permissive, authoritarian, and authoritative parenting styles which include 10 permissive, 10 authoritarian, and 10 authoritative items (Buri, 1991). Permissive parenting items include "in a well-run home children should have their way as often as parents do." An example of an item measuring authoritarian parenting includes "I do not allow my children to question the decisions that I make", whereas authoritative parenting includes items such as "once family rules have been made, I discuss the reasons for the rules with my children" and "I tell my children what they should do, but I explain why I want them to do it." Questions are based on a 5-point Likert scale ranging from 1 ("strongly disagree") to 5 ("strongly agree"). Subscale scores range from 10-50, with higher scores yielding greater appraised levels of the parental authority prototype. The PAQ was later modified for parent report and increased readability, yielding the PAQ-R for use with parents of children ages 3-8 (Reitman et al., 2002).

Highly respectable reliability and validity for the PAQ has been found (Buri, 1991). The Cronbach alpha value for internal consistency ranges from .74-.87 and test-retest reliability ranges from .77-.92 (Reitman et al., 2002). High criterion-related validity of the scale has been demonstrated due to a positive relationship between paternal

nurturance and authoritativeness, a negative relationship with authoritarianism, and no relationship with permissiveness (Buri, 1991). Discriminant-related validity is also high due to divergent responses to each of the three scales. Additionally, based on the lack of significant values of the Marlowe-Crowne Social Desirability Scale, the PAQ scores do not appear vulnerable to social desirability response bias.

Procedure

Participants were recruited from parental support groups via seven electronic list-serves throughout Ohio, Indiana, and Kentucky. After permission was granted from support group presidents, the primary investigator posted the present study on list-serves and willing participants contacted the researcher with a mailing address. Questionnaire packets were then mailed to participants and included a set of forms and questionnaires. The first form in the packet was a cover letter with informed consent (see Appendix A). This form described the types of questionnaires included in the packet and the procedures for completing them, any adverse effects from completing the questionnaires, assurance of confidentiality, and contact information. Participants were notified that participation was completely voluntary, and that completed and mailed questionnaires were understood as consent to participate. Demographic information was first collected from participants (see Appendix B). Participants then completed the CARS-P, QRS-F, CISS, SCL-90-R, and two PAQ-R (one for the child with Autism and one for the identified sibling) (see Appendices C-G). The measures were randomized (see Appendix H) and each packet contained a self-addressed, stamped envelope for participants to return. Included in the questionnaire packet was a debriefing form that was placed in a sealed envelope titled "to be opened after completing the questionnaires" and participants were

informed that reading the information in the debriefing form prior to completing the questionnaires may cause him or her to respond with bias. The debriefing form described the study in more detail, provided sources for further information, presented several support networks, offered an opportunity to request a summary of the results of the study, and provided contact information for the researcher and her advisor in case of questions or concerns (see Appendix I).

CHAPTER III

RESULTS

All analyses were performed using the statistical program, SPSS, and a significance level of 0.05. Descriptive statistics for all scales are provided in Table 1. For the purpose of this study, the phrase "child with Autism" refers to all of the children on the Autism spectrum rather than just those diagnosed with Autism.

Severity of Autistic Symptoms

The first research question explored the effects of autistic symptoms on parental functioning. The first hypothesis predicted an increase in symptoms of psychopathology in the parent as the severity of symptoms in the child with Autism increased. Pearson correlations were calculated using the CARS-P and subscales of the SCL-90-R. Significant positive correlations were found between the severity of autistic symptoms and obsessive-compulsive ($r = .26, p < .05$) and depressive symptomatology ($r = .23, p < .05$). These correlations indicate that parental symptoms of obsessive-compulsion and depression are related to the severity of symptoms in the child with Autism (see Table 2). No other significant correlations were found.

The second hypothesis predicted that measured stress would increase as the severity of symptoms in the child with Autism increased. Results indicated significant positive correlations between the severity of autistic symptoms as measured by the

Table 1

Descriptive Statistics of Measures

Variable	Possible Range	Min	Max	<i>M</i>	<i>SD</i>
CARS-P					
Symptom	14-56	18	47	33.66	5.90
Stress	14-56	18	49	29.21	7.00
QRS-F					
Parent	20-40	21	40	29.44	5.12
Pessimism	11-22	11	22	17.36	2.63
Child	15-30	16	30	22.44	3.41
Physical	6-12	6	10	7.32	1.27
Total	52-104	54	97	76.68	10.23
CISS					
Task	16-80	33	78	59.16	9.77
Emotion	16-80	21	69	41.15	11.44
Avoidance	16-80	23	70	41.63	9.59
Distract	8-40	9	32	19.37	5.52
Social	5-25	6	25	14.88	4.24
SCL-90-R					
SOM	0-4	0	2.67	0.72	0.67
O-C	0-4	0	3.10	1.14	0.80
I-S	0-4	0	2.78	0.89	0.70
DEP	0-4	0	3.46	1.09	0.81
ANX	0-4	0	2.30	0.64	0.64
HOS	0-4	0	2.83	0.76	0.72
PHOB	0-4	0	1.71	0.20	0.38
PAR	0-4	0	2.67	0.59	0.68
PSY	0-4	0	2.30	0.37	0.48
GSI	0-4	0	2.43	0.75	0.57
PST	0-90	0	76	37.51	20.65
PSDI	1-4	1	2.96	1.65	0.47

Child with Autism (N = 76)

PAQ-R

Permissive	10-50	11	38	22.44	5.15
Authoritative	10-50	31	50	39.48	3.78
Authoritarian	10-50	15	49	30.93	5.69

Identified Sibling (N = 55)

PAQ-R

Permissive	10-50	11	38	22.65	5.48
Authoritative	10-50	31	50	40.64	3.85
Authoritarian	10-50	15	49	31.27	6.26

Social Support

# Informal	0-2	0	2	1.40	0.65
# Formal	0-7	0	7	4.05	1.83
Informal Rate	1-5	2	5	3.94	0.90
Formal Rate	1-5	2	5	3.96	0.78

Table 2

Relation of the Severity of Autistic Symptoms and Stress and Parental Symptomatology as Measured by the CARS-P, the QRS-F, and the SCL-90-R

	SOM	O-C	I-S	DEP	ANX	HOS	PHOB	PAR	PSY	GSI	PST	PSDI
Autistic Symptoms	.191	.262*	.119	.232*	.134	.196	.071	.158	.030	.190	.222	.197
Parent and Family	.406**	.537**	.350**	.534**	.355**	.352**	.239*	.377**	.278*	.490**	.472**	.416**
Pessimism	.151	.231*	.056	.217	.116	.025	.171	.121	-.010	.149	.150	.122
Child Characteristics	.302*	.362**	.218	.315**	.231	.256*	.346**	.329**	.281*	.337**	.345**	.204
Physical Incapacitation	.128	.190	.032	.135	.101	.319**	.027	.092	.141	.181	.113	.175
Total Stress	.324**	.477**	.233	.424**	.271*	.327**	.252*	.322*	.228	.399**	.381**	.382**
Stress Related to Autistic Symptoms	.176	.366**	.178	.316**	.233**	.288*	.099	.266*	.118	.319**	.314**	.294*

*p < .05 **p < .01

SOM = somatization; O-C = obsessive-compulsive; I-S = interpersonal sensitivity; DEP = depression; ANX = anxiety; HOS = hostility; PHOB = phobic anxiety; PAR = paranoid ideation; PSY = psychoticism; GSI = global severity index; PST = positive symptom total; PSDI = positive symptom distress index

CARS-P and subscales of the QRS-F, including parent and family problems ($r = .50$, $p < .01$), pessimism ($r = .55$, $p < .01$), child characteristics ($r = .61$, $p < .01$), physical incapacitation ($r = .24$, $p < .05$), and total stress ($r = .74$, $p < .01$). A significant positive correlation was also found between the severity of autistic symptoms and stress directly related to autistic symptoms ($r = .68$, $p < .01$) as measured by the CARS-P. These correlations indicate that familial stress as perceived by the parent is related to the degree of autistic symptoms (see Table 3).

Additional analyses were conducted to investigate the relationship between stress and parental symptomatology. Pearson correlations were generated using the QRS-F and subscales of the SCL-90-R. Significant positive correlations were found between total stress and somatization ($r = .32$, $p < .01$), obsessive-compulsion ($r = .48$, $p < .01$), depression ($r = .42$, $p < .01$), anxiety ($r = .27$, $p < .05$), hostility ($r = .33$, $p < .01$), phobic anxiety ($r = .25$, $p < .05$), paranoid ideation ($r = .32$, $p < .05$), global severity index ($r = .40$, $p < .01$), positive symptom total ($r = .38$, $p < .01$), and positive symptom distress index ($r = .38$, $p < .01$). Significant positive correlations were also found between stress directly related to autistic symptoms as measured by the CARS-P and obsessive-compulsion ($r = .37$, $p < .01$), depression ($r = .32$, $p < .01$), anxiety ($r = .23$, $p < .05$), hostility ($r = .29$, $p < .05$), paranoid ideation ($r = .27$, $p < .05$), global severity index ($r = .32$, $p < .01$), positive symptom total ($r = .31$, $p < .01$), and positive symptom distress index ($r = .29$, $p < .01$). These correlations suggest that higher levels of stress result in greater symptoms of psychopathology in the parent. The correlations between each factor of stress and parental symptomatology reflected the same relations described above and are reported in Table 2. No other significant correlations were found.

Table 3

Relation of the Severity of Autistic Symptoms and Stress as Measured by the CARS-P and the QRS-F

	Autistic Symptoms
Parent and Family Problems	.504**
Pessimism	.554**
Child Characteristics	.605**
Physical Incapacitation	.243*
Total Stress	.741**
Stress Related to Autistic Symptoms	.681**

* $p < .05$

** $p < .01$

Coping Styles

The second research question explored the relation between various coping variables and the stress of raising a child with Autism. The first hypothesis predicted that the severity of autistic symptoms would be related to the parenting style utilized by the caregiver. Pearson correlations were calculated using the CARS-P and the PAQ-R. Results indicated no significance between the severity of autistic symptoms and parenting style (see Table 4). The second hypothesis predicted that stress was inversely related to the use of an authoritative parenting style with the child with Autism. Correlational analyses were performed using the PAQ-R and subscales of the QRS-F. Results indicated that the relation between authoritative parenting and stress was not significant (see Table 4). Because correlations were not significant, exploration into parenting styles as mediating the relation between parental stress and severity of symptoms were not performed.

Further investigation of the data was conducted between parenting style and parental symptomatology. Pearson correlations were calculated using the PAQ-R and subscales of the SCL-90-R. Significant negative correlations were found between the use of authoritative parenting with the child with Autism and obsessive-compulsion ($r = -.23$, $p < .05$), interpersonal sensitivity ($r = -.30$, $p < .05$), depression ($r = -.28$, $p < .05$), anxiety ($r = -.32$, $p < .01$), phobic anxiety ($r = .24$, $p < .05$), global severity index ($r = -.25$, $p < .05$), and positive symptom total ($r = -.30$, $p < .01$). Significant negative correlations were also found between the use of authoritative parenting with the identified sibling and obsessive-compulsion ($r = -.34$, $p < .05$), interpersonal sensitivity ($r = -.41$, $p < .01$), depression ($r = -.42$, $p < .01$), anxiety ($r = -.38$, $p < .01$), paranoid ideation

Table 4

Relation of the Severity of Autistic Symptoms and Parenting Style and Stress as Measured by the CARS-P, the PAQ-R, and the QRS-F

	Permissive	Authoritative	Authoritarian
Autistic Symptoms	.151	.030	.029
Parent and Family Problems	-.101	-.178	-.015
Pessimism	.015	-.146	-.002
Child Characteristics	-.026	-.141	.088
Physical Incapacitation	.154	-.013	-.132
Total Stress	-.108	-.113	.006
Stress Related to Autistic Symptoms	-.075	.035	-.219

($r = -.34, p < .05$), psychoticism ($r = -.37, p < .01$), global severity index ($r = -.37, p < .01$), and positive symptom total ($r = -.44, p < .01$). On the other hand, hostility was found to be positively correlated with the use of authoritarian parenting with the child with Autism ($r = .26, p < .05$) and the identified sibling ($r = .29, p < .05$). These findings indicate that as parents use more authoritative parenting techniques they report less symptoms of psychopathology (see Table 5). No other significant correlations were found.

The third hypothesis predicted that stress was inversely related to the use of task-oriented coping. Pearson correlations were generated using subscales from the QRS-F and the CISS. Significant negative correlations were found between task-oriented coping and parent and family problems ($r = -.34, p < .01$), child characteristics ($r = -.28, p < .05$), physical incapacitation ($r = -.33, p < .01$), and total stress ($r = -.33, p < .05$). Conversely, results found significant positive correlations between emotion-oriented coping and parent and family problems ($r = .50, p < .01$), pessimism ($r = .26, p < .05$), child characteristics ($r = .360, p < .01$), total stress ($r = .43, p < .01$), and stress directly related to autistic symptoms ($r = .35, p < .01$). Avoidance-oriented coping was found to be negatively correlated with physical incapacitation ($r = -.23, p < .05$). Social diversion, a subscale of avoidance-oriented coping, was negatively correlated with pessimism ($r = -.27, p < .05$), child characteristics ($r = -.24, p < .01$), and physical incapacitation ($r = -.24, p < .01$). However, the distraction subscale of avoidance-oriented coping was not related to stress. These correlations indicate that as parents use more task-oriented coping and social diversion they report less stress. Interestingly, as parents use more

Table 5

Relation of Parenting Style and Parental Symptomatology as Measured by the PAQ-R and the SCL-90-R

	Child with Autism		Identified Sibling	
	Permissive	Authoritative	Permissive	Authoritarian
SOM	-.003	-.119	.075	.212
O-C	-.014	-.233*	.023	.063
I-S	-.017	-.300**	.213	.199
DEP	.011	-.282*	.144	.166
ANX	.052	-.324**	.053	.093
HOS	-.075	-.079	.261*	.289*
PHOB	.042	-.239*	.194	.148
PAR	-.047	-.160	.100	.059
PSY	.002	-.135	.134	.138
GSI	.051	-.252*	.071	.138
PST	.019	-.304**	.088	.113
PSDI	-.063	-.118	.163	.244

*p < .05 **p < .01

SOM = somatization; O-C = obsessive-compulsive; I-S = interpersonal sensitivity; DEP = depression; ANX = anxiety;
HOS = hostility; PHOB = phobic anxiety; PAR = paranoid ideation; PSY = psychoticism; GSI = global severity index;
PST = positive symptom total; PSDI = positive symptom distress index

emotion-oriented coping they report greater stress (see Table 6). No other significant correlations were found.

Further analyses were conducted to explore the relationship between coping styles and parental symptomatology. Correlational analyses were conducted using subscales of the CISS and the SCL-90-R. Significant negative correlations were found between task-oriented coping and somatization ($r = -.37, p < .01$), obsessive-compulsion ($r = -.37, p < .01$), interpersonal sensitivity ($r = -.36, p < .01$), depression ($r = -.41, p < .01$), anxiety ($r = -.26, p < .05$), hostility ($r = -.35, p < .01$), phobic anxiety ($r = -.39, p < .01$), psychoticism ($r = -.38, p < .01$), global severity index ($r = -.36, p < .01$), and positive symptom total ($r = -.40, p < .01$). Significant positive correlations were found between emotion-oriented coping and somatization ($r = .52, p < .01$), obsessive-compulsion ($r = .67, p < .01$), interpersonal sensitivity ($r = .72, p < .01$), depression ($r = .70, p < .01$), anxiety ($r = .64, p < .01$), hostility ($r = .60, p < .01$), phobic anxiety ($r = .58, p < .01$), paranoid ideation ($r = .64, p < .01$), psychoticism ($r = .57, p < .01$), global severity index ($r = .72, p < .01$), positive symptom total ($r = .74, p < .01$), and positive symptom distress index ($r = .55, p < .01$).

Although avoidance-oriented coping was not related to symptomatology, the two subscales of this coping style showed a relation with several subscales of the SCL-90-R. The distraction subscale was positively correlated with phobic anxiety ($r = .24, p < .05$), paranoid ideation ($r = .34, p < .01$), psychoticism ($r = .25, p < .05$), global severity index ($r = .23, p < .05$), and positive symptom total ($r = .28, p < .05$). However, the social diversion subscale of avoidance-oriented coping was shown to be negatively correlated with obsessive-compulsion ($r = -.27, p < .05$), depression ($r = -.30, p < .01$), hostility

Table 6

Relation of Coping Styles and Stress as Measured by the CISS and the QRS-F

	Parent and Family Problems	Pessimism	Child Characteristics	Physical Incapacitation	Total Stress	Stress Related to Autistic Symptoms
Task-Oriented	-.335**	-.184	-.277**	-.326**	-.329*	-.012
Emotion-Oriented	.501**	.256*	.360**	.128	.426**	.346**
Avoidance-Oriented	-.103	-.193	-.100	-.233*	-.162	.031
Distraction	.059	.003	.117	-.139	.032	.129
Social Diversion	-.163	-.272*	-.243*	-.239*	-.232	-.080

*p < .05

**p < .01

($r = -.28, p < .05$), psychoticism ($r = -.23, p < .05$), global severity index ($r = -.23, p < .05$), and positive symptom distress index ($r = -.25, p < .05$). Similar to the relationship between coping styles and stress, results indicate that as parents report greater use of task-oriented coping and social diversion they report fewer symptoms of psychopathology. On the other hand, parents using more emotion-oriented coping and distraction report greater symptomatology (see Table 7). No other significant correlations were found.

Because social support is an important factor in coping with stress, further analyses were conducted to examine the relationship of social support and stress. Parents were asked to report the number of informal and formal support systems used and rate their satisfaction with the support system used longest for each. Analyses were conducted using this information and subscales of the QRS-F. Significant negative correlations were found between informal support (e.g., family and friends) ratings and parent and family problems ($r = -.27, p < .05$), child characteristics ($r = -.29, p < .05$), and total stress ($r = -.35, p < .05$). Significant negative correlations were also found between formal support (e.g., educational services, parental support groups, social services) ratings and pessimism ($r = -.31, p < .01$) and child characteristics ($r = -.28, p < .05$). No relationship was found between the number of informal and formal support systems used and stress. These findings indicate that parents who report greater satisfaction with informal and formal support systems also report less stress related to autistic symptomatology (see Table 8). The number of support systems was unrelated to stress.

Table 7

Relation of Coping Styles and Parental Symptomatology as Measured by the CISS and the SCL-90-R

	SOM	O-C	I-S	DEP	ANX	HOS	PHOB	PAR	PSY	GSI	PST	PSDI
Task-Oriented	-.365**	-.371**	-.356**	-.405**	-.258*	-.350**	-.390**	-.176	-.380**	.359**	-.400	-.199
Emotion-Oriented	.515**	.671**	.722**	.699**	.642**	.596**	.581**	.637**	.572**	.724**	.737**	.545**
Avoidance-Oriented	.064	-.033	.002	-.091	.022	-.065	.046	.146	.036	.011	.048	-.076
Distraction	.220	.196	.174	.149	.154	.141	.238*	.341**	.252*	.233*	.278*	.124
Social Diversion	-.140	-.267*	-.202	-.300**	-.136	-.281*	-.208	-.099	-.234*	-.231*	-.222	-.254

*p < .05

**p < .01

SOM = somatization; O-C = obsessive-compulsive; I-S = interpersonal sensitivity; DEP = depression; ANX = anxiety;
 HOS = hostility; PHOB = phobic anxiety; PAR = paranoid ideation; PSY = psychoticism; GSI = global severity index;
 PST = positive symptom total; PSDI = positive symptom distress index

Table 8

Relation of Social Support and Stress as Measured by Parental Self-Report and the QRS-F

	Number of Informal	Number of Formal	Informal Ratings	Formal Ratings
Parent and Family	-.008	.156	-.266*	-.107
Pessimism	.040	-.078	-.140	-.310**
Child Characteristics	-.121	.006	-.294*	-.280*
Physical Incapacitation	-.065	-.143	-.243	-.031
Total Stress	-.010	.020	-.348*	-.197
Stress Related to Autistic Symptoms	.018	-.044	-.188	-.077

* $p < .05$

** $p < .01$

The relationship between social support and parental symptomatology was also examined. Pearson correlations were calculated using parental self-report and subscales of the SCL-90-R. Significant negative correlations were found between the number of formal support systems and phobic anxiety ($r = -.26, p < .05$) and psychoticism symptomatology ($r = -.24, p < .05$). Additionally, a significant negative correlation was found between formal support ratings and phobic anxiety symptomatology ($r = -.28, p < .05$). Significant negative correlations were found between informal support ratings and obsessive-compulsion ($r = -.24, p < .05$), interpersonal sensitivity ($r = -.33, p < .01$), depression ($r = -.27, p < .05$), anxiety ($r = -.30, p < .05$), hostility ($r = -.33, p < .01$), phobic anxiety ($r = -.36, p < .01$), paranoid ideation ($r = -.30, p < .05$), psychoticism ($r = -.39, p < .01$), global severity index ($r = -.34, p < .01$), positive symptom total ($r = -.30, p < .05$), and positive symptom distress index ($r = -.30, p < .05$). These findings indicate that as parents report greater satisfaction of support systems, particularly informal support, they report less symptomatology (see Table 9). Again, the number of social support systems used was unrelated to psychopathology.

Differences in Parenting

The third research question concerned whether parents use different styles of parenting with the children with Autism and the identified siblings. The means and standard deviations of each parenting subscale as it is related to each group of children are listed in Table 10. It was hypothesized that parents would use different styles of parenting with their affected and non-affected children. A repeated measures (parenting style by child status) ANOVA was conducted. Contrary to expectations, no significant interaction between parent style and status was found, $F(2, 102) = 1.60, p > .05$.

However, a significant main effect for child status was found, $F(1, 51) = 13.93, p < .001$.

Results indicate that parents report using a greater number of parenting strategies with their non-affected children than with their children with Autism. A significant main effect for parenting style was also found, $F(2, 102) = 124.50, p < .001$. Parents use authoritative parenting more often than authoritarian and permissive styles and authoritarian parenting more often than permissive, as indicated by follow-up t-tests, $t(51) = 8.97, p < .001$, $t(51) = 20.19, p < .001$, $t(52) = 6.03, p < .001$, respectively.

Table 9

Relation of Social Support and Parental Symptomatology as Measured by Parental Self-Report and the SCL-90-R

	Number of Informal	Number of Formal	Informal Ratings	Formal Ratings
SOM	-.085	.006	-.234	-.093
O-C	.016	.013	-.283*	-.013
I-S	-.017	-.113	-.325**	-.090
DEP	-.035	-.068	-.270*	-.074
ANX	.044	-.090	-.301*	-.125
HOS	-.026	-.194	-.327**	-.099
PHOB	-.097	-.255*	-.357**	-.283*
PAR	.071	-.060	-.295*	-.022
PSY	-.169	-.238*	-.386**	-.034
GSI	-.050	-.092	-.341**	-.085
PST	-.041	-.026	-.304*	.108
PSDI	-.016	-.116	-.300*	-.029

* $p < .05$

** $p < .01$

SOM = somatization; O-C = obsessive-compulsive; I-S = interpersonal sensitivity;
 DEP = depression; ANX = anxiety; HOS = hostility; PHOB = phobic anxiety;
 PAR = paranoid ideation; PSY = psychoticism; GSI = global severity index;
 PST = positive symptom total; PSDI = positive symptom distress index

Table 10

Means and Standard Deviations of Parenting Styles as Measured by the PAQ-R

	Child with Autism N = 76	Sibling N = 55
Permissive Parenting	22.44 (5.15)	22.65 (5.48)
Authoritative Parenting	39.48 (3.78)	40.64 (3.85)
Authoritarian Parenting	30.93 (5.69)	31.27 (6.26)

CHAPTER IV

DISCUSSION

The purpose of this study was to examine the relation between the severity of autistic symptoms to parental stress levels and resulting mental health difficulties. The study also intended to identify more effective coping strategies utilized by parents of children with Autism, as evidenced by lower levels of stress and symptomatology. In doing so, this study not only examined traditional ways of coping (e.g., task-oriented, emotion-oriented, and avoidance-oriented), but parenting styles and differences in parenting between the child with Autism and his or her sibling.

Severity of Autistic Symptoms

The first research question addressed the effects of autistic symptoms on parental functioning. It was hypothesized that symptoms of psychopathology in the parent would increase as the severity of autistic symptoms in the child increased. This hypothesis was only supported in two of the nine primary symptom dimensions, as evidenced by significant positive correlations between autistic symptoms and obsessive-compulsive and depressive symptomatology. These findings support existing research that parents of a child with Autism may face difficult caregiving challenges which may increase the likelihood of mental health consequences (Seltzer et al., 2004). In fact, Weiss (2002) reported that mothers of children with Autism indicate the highest amount of depressive

symptomatology when compared to mothers of children with Mental Retardation and mothers of typically developing children. This is consistent with the present study's finding of the relationship between stress and symptoms of depression. Although previous literature indicates that parents of children with Autism often experience greater amounts of anxiety, the present study found that parents experience higher levels of obsessive-compulsion, a specific component of anxiety. A possible explanation for this finding may be that parents with a child with Autism are forced to constantly think about their child's well-being and routinely check on their child. This would explain why obsessive-compulsion was significant and overall anxiety was not. Because this study found significance in only two of the nine primary symptom dimensions, it may be that other factors contribute to parental psychopathology. For example, in the data presented here, social support and coping strategies appear to affect parental adaptation.

The second hypothesis addressed whether stress levels were related to the severity of autistic symptoms, and it was hypothesized that stress levels would increase as the severity of symptoms in the child with Autism increased. This hypothesis was fully supported, as autistic symptoms were related to all factors of stress, total stress, and stress directly related to autistic symptoms. These findings replicate existing literature that suggests that high levels of stress are associated with the task of caring for a child with Autism (e.g., Bouma & Schweitzer, 1990; Perry, 2005; Weiss, 2002). Because of the many contributing factors of stress, there are numerous possible explanations for this relationship.

First, the chronicity of the disorder may add to the stress leading to parent and family problems. Higgins et al. (2005) suggest that the permanency of Autism is associated with stress due to issues of ongoing dependency and limits on family activities. Because the severity of stress is often related to the amount of care the child requires (Bouma & Schweitzer, 1990), higher levels of stress are associated with caring for a highly dependent child (Duarte et al., 2005). In addition, the child's behavioral difficulties may result in extreme disruptions in daily family life, resulting in greater familial stress (Bouma & Schweitzer, 1990).

The implications associated with the permanency of the disorder may also contribute to parental pessimism. The child's level of functioning may dictate issues of ongoing dependency, such as the child's future and autonomy. Research indicates that parents of children with lower levels of adaptive functioning and more maladaptive behaviors display higher levels of pessimism compared to parents of children with higher levels of adaptive functioning (Bouma & Schweitzer, 1990). Although the present study did not measure the child's adaptive functioning, the severity of autistic symptoms was assessed and appears to have a similar relationship with pessimism. These results are consistent with the literature which has shown a direct relationship between the severity of autistic symptoms and maternal pessimism (Abbeduto et al., 2004).

In addition to the challenges associated with the child's adaptive functioning, difficult personality characteristics and behaviors may also contribute to stress. Existing literature indicates a significant correlation between maternal stress and the child's deviation in temperament, repetitive behaviors, and demandingness (Bouma & Schweitzer, 1990). The child's social disability, which results in deficits in emotional

expressiveness, may be another contributing factor of stress. Diminished empathy between the caregiver and the child may occur and contribute to greater amounts of parental stress.

It is not only personality characteristics and behaviors of the child with Autism that add to stress, but the degree in which the child can perform certain activities as well. Although Autism is not characterized by any physical disabilities, the relationship between autistic symptoms and physical incapacitation may be explained by the child's level of functioning. Parents of children with Autism may have to address daily care needs not experienced by parents of typically developing children of the same age (Woolfson & Grant, 2006). For instance, a child who is unable to feed or toilet him or herself may create additional stress for the caregiver. Any combination of these explanations may contribute to parental stress that may be exacerbated by the severity of autistic symptoms.

Further exploration of the data presented here showed positive correlations between stress and all primary symptom dimensions of parental symptomatology. Because parents of children with Autism report more stress than parents of typically developing children (Erguner-Tekinalp & Akkok, 2004) and children with other disabilities (e.g., Weiss, 2002), this finding is even more relevant because it indicates that parents of children with Autism may experience greater symptomatology than other parents. These results replicate existing research examining the relationship between stress and symptoms of psychopathology. Fatigue, lowered self-esteem, interpersonal dissatisfaction, helplessness, feelings of inadequacy and failure, anger, shock, guilt, frustration, and resentment are often reported by caregivers due to the stress that

accompanies raising a child with Autism (Weiss, 2002). Thus, the present study reiterates the need for parental self-care in order to successfully adapt to this stressful situation.

Coping Styles

The second research question explored the relation between various coping variables and the stress associated with raising a child with Autism. The hypothesis that the severity of autistic symptoms would be related to parenting style was not supported. Literature on parenting styles with children of other chronic disorders, such as attention deficit/hyperactivity disorder (ADHD), indicate higher levels of the use of authoritarian parenting methods (Lange et al., 2005). Similar results were expected for parents of children with Autism in the present study but were not supported. One explanation for this may be that parents of children with ADHD and parents of children with Autism have different expectations for their children. The parents of a child with ADHD may place more responsibility upon their child and therefore use more authoritarian parenting strategies when the child misbehaves. The parents of a child with Autism may use less authoritarian parenting because they may attribute the child's misbehavior to the disorder itself and may feel that trying to enforce obedience is too difficult. Additionally, because many children with Autism also have a diagnosis of Mental Retardation, the parents may feel that the child does not understand the directions given to them. Children with ADHD are typically of at least average intelligence and so parents may believe that they can understand the parental strategies associated with authoritarian parenting.

Another possible explanation for the lack of a relationship between autistic symptoms and parenting style may be that the measure used to examine parenting style is not suitable for a child with Autism. For example, statements involving verbal discussion

may not be appropriate for a nonverbal child (e.g., "I always encourage discussion when my children feel family rules and restrictions are unfair"). An instrument modified for use with a child with Autism may yield more accurate results.

It was also hypothesized that the use of authoritative parenting with the child with Autism would be inversely related to stress. Just as the severity of autistic symptoms was unrelated to parenting style, stress was also unrelated. In fact, none of the three parenting styles (authoritative, authoritarian, and permissive) were related to stress in the present study. A possible explanation for this finding may be that parenting style is not related to stress. Hastings and Beck (2004) state that there are few studies within the literature that provides direct support for a relationship between parenting behavior and parental stress. However, because the way a caregiver parents influences child outcomes (Onatsu-Arvilommi et al., 1998), which in turn is related to the amount of stress and symptomatology the caregiver experiences (Baker et al., 2003), it was predicted that this may be used as a coping strategy. It may be that although parenting style is related to child behavior problems and outcomes (Baker et al., 2003; Onatsu-Arvilommi et al., 1998), it is not directly related to parental stress.

Although parenting style was unrelated to stress, further exploration of the data found a relationship between parenting style and parental symptomatology. The use of an authoritative parenting style with both the child with Autism and the identified sibling was found to be negatively correlated with almost all symptoms of psychopathology. A possible explanation for this finding may be that children whose caregivers use this type of parenting style exhibit fewer behavior problems (Baker et al., 2003), which may reduce symptomatology in the parent. Although this relation was not originally

hypothesized, it indirectly supports the prediction that parenting style may be used as a coping strategy. It may not be used as a traditional coping mechanism because of its lack of relation with stress; however, its relation to mental health indicates the importance of its role in coping.

The third hypothesis predicted that stress would be inversely related to the use of task-oriented coping, which was supported in the present study. Three of the four factors of stress were negatively correlated with this method of coping, which is consistent with existing research that indicates successful adaptation of a stressor with the use of task-oriented coping (Hastings et al., 2005). Social diversion, a subscale of avoidance-oriented coping, was also negatively correlated with three of the four factors of stress. Because this subscale is comprised of seeking out other people (e.g., "visit a friend", "try to be with other people"), these results may be explained by research that indicates social support as an important factor in reducing stress (e.g., Kazak & Marvin, 1984; Seltzer et al., 2004). On the other hand, emotion-oriented coping was found to be positively correlated with almost all factors of stress. This is consistent with prior findings that suggest that emotion-oriented coping is highly related to distress (Endler et al., 1993). The distraction subscale of avoidance-oriented coping was unrelated to stress. A possible explanation for this finding may be that distracting oneself is not typically an option with a child who requires a lot of time and attention.

Further exploration of the data revealed a similar pattern in the relationship between coping styles and parental symptomatology. Negative correlations were found between task-oriented coping and parental symptomatology. These results are comparable to existing research that indicates that task-oriented coping does not

contribute to psychopathology (Endler et al., 1993). Also consistent with the literature is the negative correlation between the social diversion subscale of avoidance-oriented coping and many factors of parental symptomatology. According to Weiss (2002), social support is associated with parental symptomatology and feelings of adequacy in parenting. This is similar to the present study's finding of fewer symptoms of psychopathology with the use of social diversion coping strategies.

Conversely, the present study found positive correlations between emotion-oriented coping and symptoms of psychopathology in the parent. This finding is of extreme importance because it indicates that parents are reporting more symptoms of psychopathology when using this coping strategy. These results are consistent with prior findings of a relationship between this coping style and psychopathology (Endler et al., 1993). In fact, emotion-oriented coping has been found to be directly related to increased depression, isolation, and spousal relationship problems (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001). The distraction subscale of avoidance-oriented coping was also positively correlated with several factors of psychopathology. This dimension includes statements that describe avoidance of the stressor by engaging in a substitute task (e.g., "watch T.V."; "try to go to sleep"), rather than seeking out others. In existing research, avoidant coping has been described much like emotion-oriented coping and lacks the social support component that is measured in the social diversion subscale of the CISS. Therefore, this type of coping has been associated with psychological distress (Hastings et al., 2005). This is misleading because social support was measured as a factor of avoidance-oriented coping and had positive effects on stress and mental health in the present study. However, because this type of coping has been related to mental health

difficulties in the past, this study indicates that it is more beneficial to utilize social diversion as an avoidance rather than distraction.

Consistent with results from the social diversion coping style, when social support was examined, analyses found negative correlations between informal (e.g., family and friends) and formal (e.g., educational services, parental support groups, social services) support ratings and several factors of stress. In other words, as the perceived satisfaction of social support increased, stress reduced. These findings appear to be consistent with the literature that emphasizes the ameliorating effect of social support on parental stress (Weiss, 2002). The relation between social support and parental symptomatology showed a similar pattern, indicating that symptomatology diminished as the perceived satisfaction of support increased. Although negative correlations were found between informal support ratings and almost all factors of stress and psychopathology, formal support ratings were correlated with only one factor of parental symptomatology. A possible explanation for this finding may be the extreme importance placed upon informal support networks. Support from family members has shown to be powerful in reducing stress and symptomatology (Jones & Passey, 2005; Weiss, 2002). For example, Bristol (1985) found that mothers of children with Autism who received the greatest support from spouses and relatives experienced the least stress. On the other hand, results have been inconclusive regarding the effects of professional support systems on parental stress (Jones & Passey, 2005). Some research has shown beneficial results whereas others suggest increased stress with formal support systems. This may help to explain why informal support networks revealed such a strong relationship with symptomatology in the present study and that formal support systems did not.

In regards to both stress and parental symptomatology, there was no significant relation with the number of informal and formal support networks. One possible explanation for the lack of relation with external sources may be the challenge parents face in finding appropriate local services, special education facilities, and professionals in the field (Sivberg, 2002). Another possibility may be the reluctance of parents with children with Autism to utilize formal support services to a degree that is consistent with their level of need (Kazak & Marvin, 1984). Although this goes beyond the scope of the present study, an additional problem that may be created is a reliance on informal sources of support, which may create additional stress for family and friends rather than alleviating it. This may explain the present study's lack of significance between the number of either type of social support and stress and symptomatology.

Results from this study suggest that it is not the amount of social support available that is related to decreased stress and symptomatology, but the satisfaction of the support. This is evidenced by the negative correlations found between social support ratings and parental stress and symptoms of psychopathology, and the lack of a relationship between the number of social supports and stress and symptomatology. This is in contrast with previous literature stating the importance of a large social network on successful adaptation (Kazak, 1992). However, some research indicates that having even one confidant has a significant impact on mental health. It may be that parents who are extremely satisfied with one source of support tend to seek out other support systems. Therefore, as the current study suggests, the quality of support may be the most important factor, but one that also influences the attainment of other support networks.

Differences in Parenting

The fourth research question concerned whether parents use different styles of parenting with their child with Autism and the identified sibling. The hypothesis that parents use different styles of parenting between children was partially supported.

Analyses showed that parents used more strategies from all three parenting styles with the identified sibling than with the child with Autism. A possible explanation for this finding is that there are fewer strategies available for use with the child with Autism due to verbal limitations. Because Autism is defined by impairment in social interaction and communication, techniques such as verbal give and take, reason, and explaining rules may not be applicable or effective for the child with Autism. Therefore, the parent may be forced to choose from a limited number of techniques, whereas a variety of strategies are available for use with the sibling.

Although fewer strategies are used with the child with Autism, findings from the present study indicate that parents use the same style of parenting with both children. Authoritative parenting was used most frequently, followed next by authoritarian and then permissive. This pattern occurred with both the child with Autism and the identified sibling. In other words, caregivers are parenting their children in the same manner by using similar amounts of each style for both children. A possible explanation for this finding may be that parents are attempting to manage their children the same way so that one child is not being treated differently than the other. Due to the self-report nature of the study, parents may have also been more likely to report equal treatment of children for social desirability reasons.

Summary of General Findings

The current study found a direct relationship between the severity of autistic symptoms and parental stress and mental health difficulties, particularly obsessive-compulsive and depressive symptomatology. Results indicate that higher levels of stress are related to greater symptoms of psychopathology in the parent. Task-oriented and social diversion coping styles were found to be more effective ways of coping with the stress of raising a child with Autism. On the other hand, emotion-oriented and distraction coping styles were related to greater stress and symptomatology. Parents who reported greater use of authoritative parenting styles with both their children with Autism and other children in the home also report fewer symptoms of psychopathology. In addition to these coping styles, satisfaction with social support, particularly informal support systems, was found to be an important coping strategy. Parents who reported greater satisfaction with informal and formal support systems also report less stress and symptomatology. Furthermore, the present study indicates that it is the quality of support, not quantity, which is more important in reducing stress and symptomatology. The current study found that caregivers use more parenting strategies with the non-affected child; however, they do not use more of one type of parenting style with either child. Parents use greater authoritative parenting with both children than authoritarian or permissive parenting styles.

Strengths and Limitations

This study was one of the first to examine the parenting style of parents with a child with Autism as a means to cope with caregiving stress. Additionally, this is the first known study to investigate differences in parenting between the child with Autism and

his or her sibling. In order to guide future research in this area, the strengths and weaknesses of the current study must be examined. The sample used in this study is a major strength due to its size and that participants were recruited from a large region of the country. In addition, the return rate for participation in the study was 54%. Finally, this study not only examined the stress associated with caring for a child with Autism, but parental symptomatology as well.

Several important limitations were also present in this study. Although anonymity was assured, the self-report nature of the measures may have impacted the data, as parents may have been vulnerable to social desirability in their responses. Parents may have been hesitant to answer sensitive questions honestly, therefore underestimating difficulties. Another weakness of the current study is the broad range of ages for both the child with Autism and the identified sibling. Ages ranged from two to twenty-two for the child with Autism, and from one to twenty for the identified sibling. Because parenting changes as the child develops, including children of all age ranges may have affected the results of the study. It may be that parents use different styles of parenting as the child develops or parental perspectives change as the time after the child's diagnosis lengthens, but this cannot be determined with a sample with a large age range. Future research should limit the age ranges for the children in order to define a more specific sample. This would ensure that parents are raising children around the same developmental level, are facing similar parenting challenges, and have had approximately the same amount of time to adjust to the realization of their child's diagnosis of Autism. Future studies that limit age ranges may find differences in parenting.

Another limitation of the study was that most participants were older, educated, married, and of high socioeconomic status. A homogenous sample may have affected the results of the study in that there was less variability in participants. Future research should seek out participants from a variety of sources in order to achieve a varied sample. In doing so, differences in parenting style may be found. In addition, all participants were volunteers recruited from electronic support group list-serves, indicating the use of formal support systems. Individuals who volunteer for studies and belong to support groups may have fewer adjustment problems than those who do not. Thus, caution must be used when generalizing results because the current study may under-represent parental stress and symptomatology within this population.

Another weakness of the study was the use of the Parental Authority Questionnaire—Revised (PAQ-R) to examine parenting style with the child with Autism. Anecdotal responses from participants indicate that this measure was not completely applicable for the child with Autism and may have been difficult for many parents to complete. However, it is difficult to find a measure that can be used with both children with Autism and typically developing children. Future research should employ a new method of measuring parenting style. Other studies (e.g., Johnston, 1996; Johnston et al., 2002; Seipp & Johnston, 2005) examining parenting style with children with attention deficit/hyperactivity disorder (ADHD) have used observations as a means to measure parenting. This method may be helpful in future research with parents of children with Autism to gain a more accurate picture of the parenting style being used. Observational data with the identified sibling may also be gathered in order to compare parenting styles. Another option would be the use of Rickel and Biasatti's (1982) modification of Block's

(1981) Child Rearing Practices Report (CRPR), which was used in a study conducted by Woolfson and Grant (2006) measuring authoritative parenting in parents of children with developmental disabilities. Although it is the first to use this parenting measure, this study suggests that it is appropriate for use with both a developmental disability sample and a typically developing sample. The use of an alternate scale to measure parenting style for the child with Autism may yield more accurate results.

Implications

The findings from the present study not only add to the literature in this area, but have clinical significance as well. These results may be helpful in training professionals and educating caregivers in order to reduce parental stress resulting in better mental health and overall well-being. There are several notable implications from this study. First, an awareness of the relationship between the severity of autistic symptoms and stress and parental symptomatology should be gained. Parents who are raising a child with more severe symptoms of Autism need to understand that they will face additional stress that even other parents of children with Autism may not have to endure. Being aware of the effects that stress can have on parental symptoms of psychopathology may also be beneficial so parents realize the importance of self-care and effectively coping with stress. Second, professionals should encourage task-oriented coping due to parental reports of diminished stress and fewer symptoms of psychopathology. On the other hand, the use of emotion-oriented coping should be discouraged because it may actually perpetuate or maintain parental symptomatology. Existing literature indicates that parents with a child with Autism may utilize avoidance-oriented coping more frequently than other coping styles. If this is the case, it may be helpful to encourage parents who tend to

use avoidant coping methods to use social support as a distraction, rather than partake in activities alone. Third, parents should be encouraged to be highly engaged in high quality support systems rather than numerous mediocre sources of support. Results from the present study indicate that the quality of support systems is more beneficial than the quantity of support. Finally, parents should be encouraged to use authoritative parenting strategies with both their children with Autism and other children in the home due to parental report of fewer symptoms of psychopathology with the use of this parenting style.

APPENDIX A

Cover Letter and Informed Consent

Hello,

My name is Amy Lyons and I am a graduate student in clinical psychology at the University of Dayton. I am interested in researching the effects of stress on parents with an autistic child and effective ways of coping with this stress. I am very passionate about researching this disorder because I have a younger brother with Autism. Additionally, I have personally observed the stress parents (and siblings!) experience with an autistic child in the home. I understand that your time is very valuable. Please note that this is not simply a repetition of work in the field that has already been completed, but new research that may have very important clinical significance. **Your participation is completely voluntary.** You have the right to discontinue participation at any time.

Enclosed is a set of questionnaires for you. The first page is a background information form to be filled out by you. The remainder of the packet includes six assessment tools (in any order): Childhood Autism Rating Scale—Parent Version, Questionnaire on Resources and Stress—Friedrich Short Form, Coping Inventory for Stressful Situations, Symptom Checklist 90—Revised, and two (2) Parental Authority Questionnaire—Revised. One Parental Authority Questionnaire will be filled out with your autistic child in mind, while the other questionnaire will be filled out with a sibling in mind. Please indicate which form is for the autistic child and which form is for the sibling. If your autistic child has more than one sibling, please choose the sibling closest to your child's age. If your autistic child has no siblings, please fill out one Parental Authority Questionnaire. Any questions or concerns regarding the nature or procedures of this study may be discussed with Amy Lyons (Masters Level Investigator) or Dr. Carolyn Roecker Phelps (Faculty Sponsor). After thoroughly reading this cover letter, you may fill out the assessment tools. Upon completion, the questionnaires can then be mailed back in the self-addressed stamped envelope. **Completed and mailed questionnaires will be understood as your consent to participate in this study.**

No adverse effects are known to have occurred with similar research. Because only self-report measures will be used, risk is minimal. However, because you will be reporting on the stress associated with raising your autistic child, some mild distress may be experienced. If after completing these questionnaires, you recognize that your stress is

on the increase or higher than you thought, you may want to contact members of your support group or a local psychological service. Remember that you have the right to discontinue participation at any time.

Confidentiality of all information will be maintained. The only identification used in this study is the number located on the top of the papers enclosed. However, you will never be asked for your name so it is impossible to track who belongs to each number. Furthermore, only the aforementioned researchers will have access to the data and it will be stored in a locked filing cabinet.

Participating in this research project is an exciting way to further research in the field of Autism. Your contribution is vitally important and means a lot to me both professionally and personally. This will only take about an hour and a half of your time. Please feel free to contact either researcher with any questions or concerns about this study. If you have questions about your rights as a participant or to report an ethical issue with this study, you can contact the Research Review and Ethics Committee, Dr. Greg Elvers at (937) 229-2171 or Greg.Elvers@notes.udayton.edu.

Thank You!

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APPENDIX B

Demographic Information

Background Information Form

- 1) Relationship to autistic child: _____
- 2) Mother's age: _____
Father's age: _____
- 3) Mother's highest level of education completed: _____
Father's highest level of education completed: _____
- 4) Marital status: _____
- 5) Yearly income (please circle):
Less than \$20,000
\$20,000 - \$39,999
\$40,000 - \$59,999
\$60,000 - \$79,999
\$80,000 - \$99,999
\$100,000 - \$149,999
\$150,000 - \$199,999
\$200,000 or more
- 6) Formal diagnosis of child (e.g., Autistic Disorder, ASD, Asperger's Syndrome):

- 7) What type of professional diagnosed your child? (e.g., pediatrician, psychologist, psychiatrist): _____
- 8) Age of child at diagnosis: _____

9) Present age of autistic child: _____ Gender: _____

Present age of sibling (to complete one PAQ): _____ Gender: _____

10) Other siblings' age and gender:

Age: _____ Gender: _____

11) What types of formal or informal support systems do you currently use or have used in the past? (please circle all that apply and specify type of support if needed):

Spouse

Family members

Friends

Local parent support groups

Internet support group/listserve

Educational services (e.g., classroom aids, tutoring)

Social services (e.g., financial support)

Health services (e.g., speech therapy, occupational therapy)

Mental health services (e.g., individual or group therapy, assessments)

Other (please describe):

12) Using the information from the previous question, please list the type of support system, how long each has been used, and your level of satisfaction:

1

2

3

4

5

not at all

a little bit

moderately

quite a bit

extremely

satisfied

satisfied

satisfied

satisfied

satisfied

Type of Support

Length of Use

Level of Satisfaction

[illegible]

APPENDIX C

Childhood Autism Rating Scale—Parent Version

Below is a list of symptoms of Autism. Please read each one carefully, and specify a number from 1 to 4 for each item that best describes how severe that symptom is for your child. Additionally, please rate the level of stress you experience from each symptom on a scale from 1 to 4.

Please use the following rating systems:

Symptom Rating:

- 1 = normal for chronological age
- 2 = mildly abnormal
- 3 = moderately abnormal
- 4 = severely abnormal

Stress Rating:

- 1 = none at all
- 2 = a little bit
- 3 = quite a bit
- 4 = extreme

Symptoms	Symptom Rating	Stress Rating
1. Ability to relate to people (i.e., does not return interest others show in him/her)		
2. Imitation (extent to which child imitates, verbal or motor)		
3. Appropriateness of emotions (e.g., giggling, crying, etc.)		
4. Unusual body movements and/or repetitive motions or routines		
5. Unusual ways of relating to objects (e.g., spinning of cups)		
6. Difficulty with change in the environment (e.g., new living room furniture)		
7. Interest in visual information (e.g., staring at lights, avoiding eye contact)		
8. Response to sounds (i.e., overreacts or underreacts)		
9. Use of other senses (e.g., mouthing, licking, smelling, rubbing)		
10. Anxiety reaction (e.g., separation from parents, unusual fears)		

11. Verbal communication (e.g., mute, echoes, pronoun reversal, repetitive language)		
12. Nonverbal communication (e.g., use of or response to gestures)		
13. Extremes of activity level (i.e., high or low activity level)		
14. Intellectual abilities (e.g., rating 2 means even impairment in all intellectual areas; rating 4 means some areas very impaired and other areas normal)		

APPENDIX D

Questionnaire on Resources and Stress—Friedrich Short Form (QRS-F)

The questionnaire deals with your feelings about a child in your family. There are many blanks on the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions, even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do *most* of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then.

Please begin. Remember to answer all of the questions.

1. _____ doesn't communicate with others of his/her age group. T F
2. Other members of the family have to do without things because of _____ T F
3. Our family agrees on important matters. T F
4. I worry about what will happen to _____ when I can no longer take care of him/her. T F
5. The constant demands for care for _____ limit growth and development of someone else in our family. T F
6. _____ is limited in the kind of work he/she can do to make a living. T F

7. I have accepted the fact that _____ might have to live out his/her life in some special setting (e.g., institution or group home). T F
8. _____ can feed himself/herself. T F
9. I have given up things I have really wanted to do in order to care for _____ T F
10. _____ is able to fit into the family social group. T F
11. Sometimes I avoid taking _____ out in public. T F
12. In the future, our family's social life will suffer because of increased responsibilities and financial stress. T F
13. It bothers me that _____ will always be this way. T F
14. I feel tense whenever I take _____ out in public. T F
15. I can go visit with friends whenever I want. T F
16. Taking _____ on a vacation spoils pleasure for the whole family. T F
17. _____ knows his/her own address. T F
18. The family does as many things together now as we ever did. T F
19. _____ is aware who he/she is. T F
20. I get upset with the way my life is going. T F
21. Sometimes I feel very embarrassed because of _____. T F
22. _____ doesn't do as much as he/she should be able to do. T F
23. It is difficult to communicate with _____ because he/she has difficulty understanding what is being said to him/her. T F
24. There are many places where we can enjoy ourselves as a family when _____ comes along. T F

- | | | |
|--|---|---|
| 25. _____ is over-protected. | T | F |
| 26. _____ is able to take part in games or sports. | T | F |
| 27. _____ has too much time on his/her hands. | T | F |
| 28. I am disappointed that _____ does not lead a normal life. | T | F |
| 29. Time drags for _____, especially free time. | T | F |
| 30. _____ can't pay attention very long. | T | F |
| 31. It is easy for me to relax. | T | F |
| 32. I worry about what will be done with _____ when he/she gets older. | T | F |
| 33. I get almost too tired to enjoy myself. | T | F |
| 34. One of the things I appreciate about _____ is his/her confidence. | T | F |
| 35. There is a lot of anger and resentment in our family. | T | F |
| 36. _____ is able to go to the bathroom alone. | T | F |
| 37. _____ cannot remember what he/she says from one moment to the next. | T | F |
| 38. _____ can ride a bus. | T | F |
| 39. It is easy to communicate with _____. | T | F |
| 40. The constant demands to care for _____ limit my growth and development. | T | F |
| 41. _____ accepts himself/herself as a person. | T | F |
| 42. I feel sad when I think of _____. | T | F |
| 43. I often worry about what will happen to _____ when I no longer can take care of him/her. | T | F |
| 44. People can't understand what _____ tries to say. | T | F |

- | | | |
|---|---|---|
| 45. Caring for _____ puts a strain on me. | T | F |
| 46. Members of our family get to do the same kinds of things other families do. | T | F |
| 47. _____ will always be a problem to us. | T | F |
| 48. _____ is able to express his/her feelings to others. | T | F |
| 49. _____ has to use a bedpan or a diaper. | T | F |
| 50. I rarely feel blue. | T | F |
| 51. I am worried much of the time. | T | F |
| 52. _____ can walk without help. | T | F |

APPENDIX E

Coping Inventory for Stressful Situations (CISS)

The following are ways people react to various difficult, stressful, or upsetting situations.

Please specify a number from 1 to 5 for each item. Indicate how much you engage in these types of activities when you encounter a difficult, stressful, or upsetting situation.

Not at all 1 2 3 4 5 *Very much*

1. _____ Schedule my time better.
2. _____ Focus on the problem and see how I can solve it.
3. _____ Think about the good times I've had.
4. _____ Try to be with other people.
5. _____ Blame myself for procrastinating.
6. _____ Do what I think is best.
7. _____ Become preoccupied with aches and pains.
8. _____ Blame myself for having gotten into the situation.
9. _____ Window shop.
10. _____ Outline my priorities.
11. _____ Try to go to sleep.
12. _____ Treat myself to a favorite food or snack.

Not at all 1 2 3 4 5 *Very much*

13. _____ Feel anxious about not being able to cope.
14. _____ Become very tense.
15. _____ Think about how I solved similar problems.
16. _____ Tell myself that it is really not happening to me.
17. _____ Blame myself for being too emotional about the situation.
18. _____ Go out for a snack or meal.
19. _____ Become very upset.
20. _____ Buy myself something.
21. _____ Determine a course of action and follow it.
22. _____ Blame myself for not knowing what to do.
23. _____ Go to a party.
24. _____ Work to understand the situation.
25. _____ "Freeze" and not know what to do.
26. _____ Take corrective action immediately.
27. _____ Think about the event and learn from my mistakes.
28. _____ Wish that I could change what had happened or how I felt.
29. _____ Visit a friend.
30. _____ Worry about what I am going to do.
31. _____ Spend time with a special person.
32. _____ Go for a walk.
33. _____ Tell myself that it will never happen again.
34. _____ Focus on my general inadequacies.

Not at all 1 2 3 4 5 *Very much*

- 35. _____ Talk to someone whose advice I value.
- 36. _____ Analyze the problem before reacting.
- 37. _____ Phone a friend.
- 38. _____ Get angry.
- 39. _____ Adjust my priorities.
- 40. _____ See a movie.
- 41. _____ Get control of the situation.
- 42. _____ Make an extra effort to get things done.
- 43. _____ Come up with several different solutions to the problem.
- 44. _____ Take some time off and get away from the situation.
- 45. _____ Take it out on other people.
- 46. _____ Use the situation to prove that I can do it.
- 47. _____ Try to be organized so I can be on top of the situation.
- 48. _____ Watch TV.

APPENDIX F

Symptom Checklist—90—Revised (SCL-90-R)

Below is a list of problems people sometimes have. Please read each one carefully, and specify a number from 1 to 5 for each item that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY.

0	1	2	3	4
<i>not at all</i>	<i>a little bit</i>	<i>moderately</i>	<i>quite a bit</i>	<i>extremely</i>

HOW MUCH WERE YOU DISTRESSED BY:

1. _____ Headaches
2. _____ Nervousness or shakiness inside
3. _____ Repeated unpleasant thoughts that won't leave your mind
4. _____ Faintness or dizziness
5. _____ Loss of sexual interest or pleasure
6. _____ Feeling critical of others
7. _____ The idea that someone else can control your thoughts
8. _____ Feeling others are to blame for most of your troubles
9. _____ Trouble remembering things
10. _____ Worried about sloppiness or carelessness
11. _____ Feeling easily annoyed or irritated
12. _____ Pains in heart or chest
13. _____ Feeling afraid in open spaces or on the streets
14. _____ Feeling low in energy or slowed down
15. _____ Thoughts of ending your life

1 2 3 4 5
not at all a little bit moderately quite a bit extremely

HOW MUCH WERE YOU DISTRESSED BY:

16. _____ Hearing voices that other people do not hear
17. _____ Trembling
18. _____ Feeling that most people cannot be trusted
19. _____ Poor appetite
20. _____ Crying easily
21. _____ Feeling shy or uneasy with the opposite sex
22. _____ Feelings of being trapped or caught
23. _____ Suddenly scared for no reason
24. _____ Temper outbursts that you could not control
25. _____ Feeling afraid to go out of your house alone
26. _____ Blaming yourself for things
27. _____ Pains in lower back
28. _____ Feeling blocked in getting things done
29. _____ Feeling lonely
30. _____ Feeling blue
31. _____ Worrying too much about things
32. _____ Feeling no interest in things
33. _____ Feeling fearful
34. _____ Your feelings being easily hurt
35. _____ Other people being aware of your private thoughts
36. _____ Feeling others do not understand you or are unsympathetic
37. _____ Feeling that people are unfriendly or dislike you
38. _____ Having to do things very slowly to insure correctness
39. _____ Heart pounding or racing
40. _____ Nausea or upset stomach
41. _____ Feeling inferior to others
42. _____ Soreness of your muscles

1 2 3 4 5
not at all a little bit moderately quite a bit extremely

HOW MUCH WERE YOU DISTRESSED BY:

- 43. _____ Feeling that you are watched or talked about by others
- 44. _____ Trouble falling asleep
- 45. _____ Having to check and double-check what you do
- 46. _____ Difficulty making decisions
- 47. _____ Feeling afraid to travel on buses, subways, or trains
- 48. _____ Trouble getting your breath
- 49. _____ Hot or cold spells
- 50. _____ Having to avoid certain things, places, or activities because they frighten you
- 51. _____ Your mind going blank
- 52. _____ Numbness or tingling in parts of your body
- 53. _____ A lump in your throat
- 54. _____ Feeling hopeless about the future
- 55. _____ Trouble concentrating
- 56. _____ Feeling weak in parts of your body
- 57. _____ Feeling tense or keyed up
- 58. _____ Heavy feelings in your arms or legs
- 59. _____ Thoughts of death or dying
- 60. _____ Overeating
- 61. _____ Feeling uneasy when people are watching or talking about you
- 62. _____ Having thoughts that are not your own
- 63. _____ Having urges to beat, injure, or harm someone
- 64. _____ Awakening in the early morning
- 65. _____ Having to repeat the same actions such as touching, counting, or washing
- 66. _____ Sleep that is restless or drained
- 67. _____ Having urges to break or smash things
- 68. _____ Having ideas or beliefs that others do not share
- 69. _____ Feeling very self-conscious with others

1 2 3 4 5
not at all a little bit moderately quite a bit extremely

HOW MUCH WERE YOU DISTRESSED BY:

- 70. _____ Feeling uneasy in crowds, such as shopping or at a movie
- 71. _____ Feeling everything is an effort
- 72. _____ Spells of terror or panic
- 73. _____ Feeling uncomfortable about eating or drinking in public
- 74. _____ Getting into frequent arguments
- 75. _____ Feeling nervous when you are left alone
- 76. _____ Others not giving you proper credit for your achievements
- 77. _____ Feeling lonely even when you are with people
- 78. _____ Feeling so restless you couldn't sit still
- 79. _____ Feelings of worthlessness
- 80. _____ The feeling that something bad is going to happen to you
- 81. _____ Shouting or throwing things
- 82. _____ Feeling afraid you will faint in public
- 83. _____ Feeling that people will take advantage of you if you let them
- 84. _____ Having thoughts about sex that bother you a lot
- 85. _____ The idea that you should be punished for your sins
- 86. _____ Thoughts and images of a frightening nature
- 87. _____ The idea that something serious is wrong with your body
- 88. _____ Never feeling close to another person
- 89. _____ Feelings of guilt
- 90. _____ The idea that something is wrong with your mind

APPENDIX G

Parental Authority Questionnaire—Revised (PAQ-R)

Please check: _____ autistic child _____ sibling

For each statement below circle the number that best describes YOUR BELIEFS ABOUT PARENTING YOUR CHILD. There are no right or wrong answers. We are looking for your overall impression regarding each statement. Please specify a number from 1 to 5 for each item.

1	2	3	4	5
<i>strongly disagree</i>	<i>disagree</i>	<i>neither agree</i>	<i>agree</i>	<i>strongly agree</i>
		<i>or disagree</i>		

1. _____ In a well-run home children should have their way as often as parents do.
2. _____ It is for my children's own good to require them to do what I think is right, even if they don't agree.
3. _____ When I ask my children to do something, I expect it to be done immediately without questions.
4. _____ Once family rules have been made, I discuss the reasons for the rules with my children.
5. _____ I always encourage discussion when my children feel family rules and restrictions are unfair.
6. _____ Children need to be free to make their own decisions about activities, even if this disagrees with what a parent might want to do.
7. _____ I do not allow my children to question the decisions that I make.

1	2	3	4	5
<i>strongly disagree</i>	<i>disagree</i>	<i>neither agree</i>	<i>agree</i>	<i>strongly agree</i>
<i>or disagree</i>				

8. _____ I direct the activities and decisions of my children by talking with them and using rewards and punishments.
9. _____ Other parents should use more force to get their children to behave.
10. _____ My children do not need to obey rules simply because people in authority have told them to.
11. _____ My children know what I expect from them, but feel free to talk with me if they feel my expectations are unfair.
12. _____ Smart parents should teach their children early exactly who is the boss in the family.
13. _____ I usually don't set firm guidelines for my childrens' behavior.
14. _____ Most of the time I do what my children want when making family decisions.
15. _____ I tell my children what they should do, but I explain why I want them to do it.
16. _____ I get very upset if my children try to disagree with me.
17. _____ Most problems in society would be solved if parents would let their children choose their activities, make their own decisions, and follow their own desires when growing up.
18. _____ I let my children know what behavior is expected and if they don't follow the rules they get punished.
19. _____ I allow my children to decide most things for themselves without a lot of help from me.
20. _____ I listen to my children when making decisions, but I do not decide something simply because my children want it.
21. _____ I do not think of myself as responsible for telling my children what to do.
22. _____ I have clear standards of behavior for my children, but I am willing to change these.
23. _____ I expect my children to follow my directions, but I am always willing to listen to their concerns and discuss the rules with them.

1	2	3	4	5
<i>strongly disagree</i>	<i>disagree</i>	<i>neither agree</i>	<i>agree</i>	<i>strongly agree</i>
<i>or disagree</i>				

24. _____ I allow my children to form their own opinions about family matters and let them make their own decisions about those matters.

25. _____ Most problems in society could be solved if parents were stricter when their children disobey.

26. _____ I often tell my children exactly what I want them to do and how I expect them to do it.

27. _____ I set firm guidelines for my children but I am understanding when they disagree with me.

28. _____ I do not direct the behaviors, activities, or desires of my children.

29. _____ My children know what I expect of them and do what is asked simply out of respect for my authority.

30. _____ If I make a decision that hurts my children, I am willing to admit that I made a mistake.

APPENDIX H

Randomization of Measures

Measures:

CARS-P = A

QRS-F = B

CISS = C

SCL-90-R = D

PAQ (1) = E

PAQ (2) = F

Random Order:

ABCDEF, BCDEFA, CDEFAB, DEFABC, EFABCD, EFABCD, etc.

APPENDIX I

Debriefing Form

****Reading this information before completing the questionnaires may cause you to respond to the questions with bias. Please complete questionnaires before reading.****

Information about the Study

This study is designed to better understand the stress associated with raising a child with Autism and the impact on one's psychological well-being. The focus of this study is to look at the types of coping used to deal with this stress and the differences in parenting styles used with the autistic child and his or her sibling. This information will then be analyzed to see which coping and parenting style best predicts one's level of stress and psychological well-being.

Raising a child with a developmental disability, such as Autism, constitutes a significant stressor for caregivers. In fact, research has shown that parents of a child with a developmental disability report disproportionately greater levels of stress than parents of children without a developmental disability (e.g., Erguner-Tekinalp & Akkok, 2004; Hastings et al., 2005; Perry, Harris & Minnes, 2005; Weiss, 2002). Parenting an autistic child is even *more* stressful than parenting children with other disabilities because the etiology is unknown (Perry, Harris & Minnes, 2005). The severity of autistic symptoms in the child may be related to the level of stress experienced by the caregivers. One of the questionnaires you completed measures the severity of your child's Autism and another questionnaire measures the amount of stress you experience. Because stress impacts psychological symptoms, you also completed a questionnaire assessing your current psychological well-being.

In order to successfully adapt to the stress associated with raising an autistic child, parents must use as many effective coping strategies as possible. According to Endler and Parker (1990b), people cope with stress in three main ways: (1) task-oriented coping (i.e., strategies that attempt to solve a problem, reconceptualize a problem, or minimize the effects of a problem), (2) emotion-oriented coping (i.e., emotional responses, self-preoccupation, and fantasizing reactions), and (3) avoidance-oriented coping (i.e., strategies that involve avoiding a stressful situation by seeking out others or those that involve engaging in a substitute task). Task-oriented coping has been related to

adaptation, whereas emotion-oriented coping has been associated with psychological distress. The coping inventory you completed will assess your coping style in terms of being task-oriented, emotion-oriented, or avoidance-oriented.

One coping strategy that may be used to deal with increased stress is the style of parenting used with the autistic child. It may also play a role in determining why some caregivers feel more overburdened than others in the task of raising a child with Autism. According to Baumrind (1966), there are three types of parenting styles: (1) permissive, (2) authoritarian, and (3) authoritative. The permissive parent is accepting of the child's impulses, desires, and wishes and rarely uses punishment. The authoritarian parent attempts to shape and control the child's behavior and attitudes in accordance with a set standard of conduct. The authoritative parent uses reason, power, and reinforcement with the child and does not base decisions on the child's desires. Please keep in mind there is no one correct method of parenting. The parenting questionnaires you completed for your autistic child and his or her sibling will be assessed to determine the type of parenting used with each child.

For further information about this area of psychological research, you may read the sources below. If you are interested in a full listing of references cited above, please let me know and I will make them available for you.

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Contact Information

If you have any questions or concerns about the research project, you can contact Amy Lyons at (502) 295-0190 or lyonsamm@notes.udayton.edu or Dr. Carolyn Roecker Phelps at (937) 229-2618 or carolyn.roecker-phelps@notes.udayton.edu. You may also contact the chair of the Research Review and Ethics Committee, Dr. Greg Elvers at (937) 229-2171 or greg.elvers@notes.udayton.edu if you have any questions about your rights as a participant or to report an ethical issue with this study.

Support Networks

There are many support services available for parents of children with Autism. I encourage you to continue participation in any groups of which you are a member. If you would like to find additional resources, please see the following websites:

www.autism-society.org
www.autismspeaks.org
www.NationalAutismAssociation.org
www.feat.org
www.kylestreehouse.org

Results

If you would like to receive the results of this study, please send your name and address or email address **on a separate sheet of paper** so that your name will not be associated with your questionnaire information. I would be more than happy to mail you the results.

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