

Adolescent Coping and Family Functioning in the Family of a Child with Autism

by

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For Mom, Debbie, Dan, Sam, and Audrey

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## ABSTRACT

Adolescent Coping and Family Functioning in the Family of a Child with Autism

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Autism is on the rise at an alarming rate. Autism impacts all members of a family including siblings. There is much research that examines the etiology of autism but there is little research that explores, from the sibling perspective, what it is like to have a sibling with autism. There are studies that examine coping and the perception of family functioning from the parent perspective, but there are few studies that examine coping and perception of family functioning from the adolescent perspective. The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) guided this exploratory, correlational study. The purpose of this study was to examine the coping strategies used by adolescent siblings of children with autism and to examine how these coping strategies influence their perception of family functioning. Qualitative data were collected to help inform the quantitative results. Adolescents 11-21 years of age were recruited through the Interactive Autism Network and completed the measures online via Survey Monkey. The most commonly used coping strategy, as measured by A-COPE, for adolescents in this study was seeking diversion. Females more frequently than



males used the coping strategies developing social support, investing in close friends, and relaxing. The younger adolescents used an increased number of and more varied coping strategies than older adolescents. The adolescents perceived that their families functioned in the unhealthy range on five of the seven subscales on the *Family Assessment Device* with no statistically significant differences between males and females or between age groups on perception of family functioning. Path analysis using multiple regression revealed significant negative relationships between coping strategies, self-concept, satisfaction with the sibling relationship, and family functioning and explained 44.2% of the variance in the proposed model. The results of this study provide a better understanding of the complexities that adolescents who have siblings with autism encounter. Further research is needed to explore additional factors that influence family functioning including examining family functioning with adolescents with typically developing siblings. The development of coping strategies in children and adolescents also needs further exploration.

## **Introduction**

The prevalence of autism is on the rise at an alarming rate. Although the diagnosis of autism has been described in the medical literature since the 1940's, the increasing prevalence of autism has brought the disease to the attention of healthcare providers, scientists, and the public. The prevalence of autism has increased from 1 in 166 in 2003 to 1 in 150 today (ASA, 2009). This significant rise in the number of children with autism is creating not only an economic burden on society but also a national health crisis (ASA).

Autism is a medical condition that impacts an entire family. While there are studies that examine coping strategies and family functioning in parents and school age siblings of children with disabilities, very little research examines family functioning and coping strategies used by adolescents who have a sibling with a disability. Even fewer studies examine coping strategies and family functioning in siblings of children with autism. The studies that examine the concepts of coping and family functioning report inconsistent findings as to the impact on siblings of living with a brother or sister with a disability or chronic illness. Since the diagnosis of autism is on the rise, it is imperative that nurses understand experiences of adolescents who have siblings with autism including their coping strategies and perception of family functioning.

## **Purpose and Specific Aims**

While much research is directed at finding a cause for autism, there is limited research examining the coping strategies used by adolescent siblings when there is a child with autism in the home. There is also limited information regarding how adolescents who have a sibling with autism perceive that their family functions. The purpose of this exploratory, correlational study was to examine the coping strategies used by adolescent siblings of children with autism and to examine how these coping strategies influence their perception of family functioning. In addition, the self concept of the adolescent was examined to explore the relationship among self concept and coping strategies that are used by the adolescent. This research study lays a foundation for future intervention research aimed specifically at adolescents and their family to promote positive coping strategies and a healthy, positive perception of family functioning. The specific aims along with related research questions and hypotheses include:

**Aim 1.** Explore, from the adolescent perspective, the experience of being in a family with a child with autism.

**Research Question 1.1:** What are the experiences described by adolescents of living in the family with a child with autism?

**Aim 2.** Determine coping strategies used by adolescents who have a sibling with autism.

**Research Question 2.1:** What coping strategies do adolescents who have a sibling with autism use as assessed by the Adolescent Coping Orientation for Problem Experiences (A-COPE)?

**Research Question 2.2:** Do adolescent males use different coping strategies than adolescent females when they have a sibling with autism when measured using A-COPE?

**Hypothesis 2.1:** Younger adolescents use fewer coping strategies compared to older adolescents as measured by A-COPE.

**Aim 3.** Determine how adolescents with siblings with autism perceive their family functioning.

**Research Question 3.1:** How do adolescents who have a sibling with autism perceive that their family is functioning as measured by the Family Assessment Device (FAD)?

**Research Question 3.2:** Do the perceptions of family functioning of adolescents who have siblings with autism differ by age and gender?

**Aim 4.** Determine the predictive ability of the proposed model (see Appendix D)

**Research Question 4.1:** How do the variables of coping strategies, perception of family functioning, self concept, and satisfaction with the sibling relationship relate to each other for adolescents who have siblings with autism?

### **Format for Dissertation**

The dissertation consists of a three article format. The first article discusses the concept of coping and explores the coping strategies that are used by adolescents who have a sibling with autism. The second article explores the adolescent perception of family functioning when there is a child with autism in the family. In the third article, the proposed model is tested to ascertain if the age and gender of the adolescent influences

their coping strategies, self concept, and satisfaction with the relationship with their sibling with autism. The model examines the influence of the adolescent's self concept and satisfaction with their sibling relationship to determine if they influence the coping strategies that adolescents use. The model also tests how these variables impact the adolescent's perception of family functioning. The constant comparative method of analysis was used to identify common themes related to: 1) what adolescent siblings of children with autism are coping with and how they are coping; 2) how this influences their self-perception; 3) how this influences their relationship with their sibling with autism; and 4) how this influences their perception of family functioning. The qualitative data are infused throughout the results sections as they relate to the three chapters.

An exploratory, correlational design with a convenience sample of 97 adolescents 11-20 years old who are siblings of children with autism addressed the specific aims of this study. An exploratory design was necessary as there are few research studies examining coping from the adolescent perspective or how these adolescents perceive family functioning.

The study was designed to have a power of at least 80% with an alpha of .05 to detect a moderate (.30) correlation as described by Polit (1996). The siblings were recruited from the Interactive Autism Network (IAN) Community web site which is part of the Krieger Institute ([www.ianproject.org](http://www.ianproject.org)). The IAN allows researchers to recruit study subjects on their community web site with proper Human Subjects Internal Review Board (HSIRB) permission as well as a letter from the doctoral school of study.

## **Review of the Literature**

Autism was first described by Kanner in 1943. He presented the cases of 11 children whom he believed had a new syndrome that was distinct from the assigned diagnosis of schizophrenia (Gallagher, et al. 2003; Rau, 2003). Kanner's autistic children displayed behaviors that demonstrated deficits in social interaction and communication skills that are now recognized as hallmark deficits of autism (Brimacombe, Xue, & Parikh, 2007; Rau, 2003; Rosen, Yoshida, & Croen, 2007). Males are more frequently affected with autism than females with a ratio of 4.3:1 (ASA, 2009).

Although it is believed that autism crosses all races and ethnicities, little is known about the prevalence rates of autism by race and ethnicity (Newschaffer et al. 2007). Newschaffer et al. reported that a study conducted in California found that the prevalence rate was higher in children with black mothers, lower in children with Mexican born mothers, and comparable among children with white, Asian, and U.S. born Hispanic mothers. Schieve, Rice, and Boyle (2006) have reported that autism rates are comparable in black and white children and lower in Hispanic children.

While much research has been directed at finding a cause for autism, there is limited research examining the coping strategies used by family members when there is a child with autism in the home; even less is known regarding how adolescents who have a sibling with autism perceive that their family functions. In this chapter, a review of the literature is presented by first describing the challenges of living with a sibling with autism, the importance of the sibling relationship, the sibling outcomes when living with

a child with a disability, and the developmental considerations of the adolescent siblings. The concept of coping is discussed as it relates to the relevant stages of cognitive development of adolescents. More focused attention is devoted to what the literature reveals about coping strategies employed by the families affected by autism and chronic illness. Finally, the concept of family functioning is explored as well as an explanation of the theoretical framework that guided this study.

### **Challenges of living with a child with autism in the family.**

Families face many challenges when living with a child with a disability. Parents of a child with autism, face numerous challenges including, the burden of caring for the child, the physical toll that this care entails, the financial burdens due to one parent staying home as caregiver, the effects of social isolation, and marital strain (Dumas, Wolf, Fisman, & Culligan, 1991; Gray, 1998; Hodgkinson & Lester, 2002; Krulik et al. 1999; Melnyk, Feinstein, Moldenhouer, & Small, 2001; Scorgie & Sobsey, 2000). Due to the nature of the disorder and the behaviors that the children display, parenting a child with autism is a demanding task. Children with autism display inappropriate social behavior, act aggressively towards themselves or others, engage in repetitive, self stimulatory behaviors, have erratic sleep patterns, show marked decrease in language, communication and affection, and 75-80% exhibit cognitive delays (Gray; Rau, 2003; Tomanik, Harris, & Hawkins, 2004). Parents also report challenges in teaching basic life skills to their

children with autism as well as protecting them from danger and preparing them for adult life (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004).

Children also face challenges when living with a sibling with autism. A qualitative study conducted by Hutton and Caron (2005) found that parents try to help siblings deal with having a sibling with autism in several ways. Parents reported that they tried to educate the siblings about autism, spend time with the unaffected sibling away from the child with autism, involve siblings in the therapy for the autistic child and protected unaffected siblings from harm if there was a threat of danger by the sibling with autism. The Autism Society of America (2007) reports that siblings of children with autism report the following sources of stress: embarrassment around peers; jealousy regarding the amount of time that parents spend with the sibling with autism; frustration when they do not get a response from the sibling with autism when attempting to interact with them; being the target of aggressive behaviors; attempting to make up for the deficits of the sibling with autism; concern for parent's stress and grief; and concern over their role in future care giving.

### **Importance of the sibling relationship.**

Sibling relationships are among the most important, dynamic and long lasting relationships that a child will have and lay the foundations for peer and adult relationships (Cox, Marshall, Mandleco, & Olsen, 2003; Dellve, Cernerud, & Hallberg, 2000; Hamama et al. 2000; Harris & Glasberg, 2003; Lobato, Faust, & Spirito, 1989;



McHale & Gamble, 1987; McHale & Gamble, 1989; Rodrigue, Geffken, & Morgan, 1993). Cox et al. reported that by the time children are one year of age, they have spent more time interacting with their siblings than their fathers.

The longevity of the sibling relationship is unparalleled in any other relationship. These longitudinal relationships influence not only the cognitive, affective, and social skills, but also the development of a positive self concept of the siblings. The sibling relationship has a significant impact on child socialization and makes it possible to express feelings and to experience friendships, loyalty, rivalry, and support (Harris & Glasberg, 2003; Verté, Roeyers, & Buysse, 2003). It is in this relationship that children learn new roles of teacher, caregiver or leader for younger or less capable siblings (McHale & Gamble, 1987). With the changing structure of the family in which single parent and dual wage earner households continue to increase, the sibling relationship is even more important. Siblings rely more on each other in single parent families, as well as in families in which both parents work outside the home (Morrison, 1997).

Children with disabilities are surviving longer and are more likely to receive care in the home rather than in an institution. This increases the likelihood that siblings will be impacted by living each day with a sibling with a disability (Cox et al. 2003). The care that children with autism need is ongoing. As parents age, siblings become a likely source of care for the child with autism which can cause anxiety in the adolescent who is able to look toward the future and anticipate potential caregiving responsibilities (Harris & Glasberg, 2003).

Sharpe and Rossiter's (2002) meta-analysis of siblings of children with chronic illness concluded that more methodologically sophisticated studies of siblings of children with disabilities are needed. For example, many studies rely on parent reports (i.e. proxy data) of sibling feelings, although the literature is clear that parents are not always aware of the siblings' feelings (Gallo, Breitmayer, Knafl, & Zoeller, 1991; Gallo & Szyclinski, 2003; Guite, Lobato, Kao, & Plante, 2004; Hamama et al., 2000; Hayes, 1997; Sharpe & Rossiter, 2002). The sibling relationship is filled with both conflict and companionship in the best of circumstances. One solution is to ask the siblings directly about their relationship with their sibling with a disability rather than rely on proxy informants (i.e. parents). Further examination of the influence of living with a child with a disability from the well sibling's perspective would add to the body of knowledge.

### **Sibling outcomes when living with a child with a disability.**

Research findings on the impact of living with a sibling with a disability are contradictory. Further, specific studies that examine the impact of autism are especially scarce. Expanding the audience to siblings of children with disabilities revealed that, as with the siblings of children with autism, there are negative as well as positive effects on children who have a sibling with a disability. The negative effects of having a sibling with a disability include higher risk for depression (Cox et al. 2003; Gupta & Singhal, 2006; Kaminsky & Dewey, 2002; Mascha & Boucher, 2006; McHale & Gamble, 1987), anxiety (McHale & Gamble, 1987), decreased self esteem (Dyson, 1999; McHale &

Gamble, 1987), isolation and feelings of loneliness (Dellve et al. 2000; Glasberg, 2000; Gupta & Singhal; Sloper, 2000), loss of parental attention (Dyson, 1999; Gupta & Singhal; Leonard, 1991; McHale & Gamble, 1987; Rodrigue et al. 1993), changes in family roles, structure, and activities including more caretaking roles (Dyson, 1999; Gupta & Singhal; Leonard, 1991; Mascha & Boucher, 2006; McHale & Gamble, 1987; Rodrigue et al., 1993), feelings of guilt and shame (Gupta & Singhal; Rodrigue et al. 1993), maladjustment (Cox et al. 2003), behavior problems (Cox et al. 2003; Verté et al. 2003), embarrassment surrounding the sibling's behaviors (Gupta & Singhal; Mascha & Boucher, 2006) and worries and anxieties related to the disabled sibling's welfare (Mascha & Boucher, 2006; McHale & Gamble, 1987).

On the other hand, other studies reveal that there are some positive aspects that children who have a sibling with a disability display including a positive self concept (Kaminsky & Dewey, 2002; Mates, 1990; Rodrigue et al. 1993), enhanced caretaking skills (Mates, 1990), increased sympathy, empathy, and compassion (Sharpe & Rossiter, 2002; Sloper, 2000), personal maturation (Mascha & Boucher, 2006; McHale & Gamble, 1987; Sloper, 2000), and increased family cohesion (Sloper, 2000). Given the contradictory nature of these findings, further study is needed to explore the influence of living with a sibling with a disability such as autism.

### **Developmental considerations and siblings.**

Adolescence is a complex time. Adolescent lives are filled with challenges ranging from normative challenges of arguing with parents or breaking up with a significant other to challenges of dealing with chronic stressors such as poverty or living with a sibling with autism (Harris & Glasberg, 2003; Patterson & McCubbin, 1987; Skinner & Zimmerman-Gembeck, 2007). Rodrigue et al. (1993) reported that having a sibling with autism is more difficult than having a sibling with any other disability.

When examining siblings' responses to living in a family with a disabled child, the psychosocial and cognitive developmental status of the sibling needs to be considered. According to Erikson, adolescents, between 12 and 18 years of age, are developing a sense of identity (Hockenberry, Wilson, & Winkelstein, 2005). Adolescents are beginning to see themselves as individuals who are unique with their own personal identities. A sense of belonging to or being accepted by a group is an essential prelude to developing a personal identity. As adolescents develop their identity, they often separate from their families. In high school, adolescents are spending less time with family and more time with peers. After high school graduation, adolescents typically leave home to either attend college or begin a job. Having a sibling with a disability makes the developmental task of separating from the family extremely difficult as the adolescent feels guilty about leaving the remainder of the family to care for the sibling with a disability (McHugh, 2003). Adolescents may choose to spend more time at home and attend a college or obtain work near to their home.

Cognitive development also plays an important role in the adolescent's understanding the dynamics of a family with a child with autism. Adolescents who are 11 years of age and older are in the formal operations stage according to Piaget (Hockenberry et al. 2005). They are able to think beyond the present and can imagine a sequence of events (Hockenberry et al. 2005), such as who will take care of their sibling with autism when their parents no longer can. Adolescents in this stage also wonder what others think of them and believe that everyone is focusing on the same things they are-themselves and their activities (Bastable, 2006). This imaginary audience has influence over the adolescent and explains in part why adolescents are self conscious. Having a sibling with autism who does not conform to the accepted norms of society can be a source of embarrassment (E. Mellem, personal communication, March 8, 2006) for the adolescent sibling who is trying to fit in with their peers.

Adolescents in the formal operations stage also believe that they are invincible which leads to risk taking behaviors. This normal phase of development coupled with the potential for risks related to living with a sibling with autism such as increased incidence of depression, isolation, and anxiety, increase the need to be vigilant about recognizing that these children may need additional support and guidance (Bastable, 2006; Cox et al. 2003; Dellve et al., 2000; Glasberg, 2000; Gupta & Singhal, 2006; Kaminsky & Dewey, 2002; Mascha & Boucher, 2006; McHale & Gamble, 1987; Sloper, 2000)).

Glasberg's (2000) research (based in the psychosocial and cognitive development of Erikson and Piaget) indicates that siblings of different ages (5-17 years) had different

understandings regarding their sibling with autism. Glasberg found that children of all ages had lower levels of cognitive sophistication when discussing illness. In Glasberg's study, 5% of 11-17 year olds reported that they had never heard autism or Asperger's Syndrome as their sibling's diagnosis. This is in contrast with the 90% of parents who predicted that their child would be familiar with the diagnostic terms autism or Asperger's suggesting that there is a difference between telling and understanding when working with children who have a sibling with autism or other disabilities. Despite the fact that the adolescents in Glasberg's study were not cognitively sophisticated, they were able to evaluate the implications of having a sibling with autism and to envision future issues related to having a sibling with autism.

All adolescents, those from families with or without children with disabilities, display a range of reactions from maturity in some situations to childlike behavior in others (Hockenberry et al. 2005). As adolescents become older, they develop control of their emotions and can approach situations more calmly and rationally (Hockenberry et al. 2005). This often results in more mature discussions regarding what they are thinking and feeling in response to having a sibling with autism. The ability to have more mature discussions makes exploring the coping strategies and perception of family functioning appropriate for the adolescent population.

### **Development of coping.**

Coping strategies are generally believed to develop during childhood and become more sophisticated as the child matures. However, children's coping strategies are not well understood or studied from a developmental perspective (Glasberg, 2000; Hamama et al., 2000; Lerner & Benson, 2003; Ryan, 1989). There are several reasons for the difficulty in studying the development of coping. First, there is no clearly identified theory for examining coping in children or adolescents (Ryan, 1989). Second, the majority of the studies that examine coping and children have not focused specifically on coping as it relates to the development of coping strategies, that is to say, within the context of the child's continued emotional and cognitive growth and change. Third, most of this literature uses the stress and coping model and applies it to the child who has a disabled sibling without taking into account the child's developmental level (Houtzager et al., 2004).

As children mature cognitively and emotionally they are better able to problem solve and channel their emotions. Accordingly, the coping strategies that children use are dependent on age and developmental level, as well. Skinner and Zimmer-Gembeck (2007) reviewed studies that examined age differences or changes in coping responses to stress. Transition periods for coping were identified including: late childhood to early adolescence (10-12); early and middle adolescence (12-16); and middle and late adolescence (16-22). Between the ages of 5-7 and 8-12 years, the most rapid development of coping occurred. During the younger years, coping is carried out by

using direct action and enlisting the help of others as needed. This trend of seeking help from others continues as children move into adolescence.

As children reach middle childhood and their cognitive development progresses, they are able to use more sophisticated techniques for coping such as distraction, delay, and problem solving, either independently or with guidance from others. By adolescence, children's cognitive development should be in formal operations, enabling adolescents to more effectively problem solve and to regulate their coping responses and anticipate future implications of decisions. Adolescents are also able to determine which adults will be best able to help them in a given situation (Skinner & Zimmer-Gembeck, 2007).

Coping is shaped in part by social relationships and contexts. Children's coping abilities develop in part by socialization and exposure to others who provide models of coping. Parents and other social supports may either be stressors themselves or may strive to buffer children from repeated stressors. Parents are also instrumental in role modeling both constructive and unconstructive strategies for coping (Skinner & Zimmer-Gembeck, 2007; Zimmer-Gembeck & Locke, 2007). Ryan (1989) stated that "both adaptive and maladaptive coping strategies are learned behaviors and can be acquired, changed, or eliminated" (p. 111). Future research needs to examine how children's coping strategies shape their social relationships, as well as the impact that those coping strategies have on their development into adulthood (Clarke, 2006).



### **Coping with autism and chronic illness.**

Coping is a complex phenomenon that is not fully understood particularly for families of autistic children. Although a plethora of literature examines parental coping in a variety of pediatric populations, information specific to siblings of children with childhood autism is limited. Much of the research relies on the definition of coping set forth by Lazarus and Folkman (1984) who defined coping as the “constantly changing cognitive and behavioral efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 141).

Gray (1998) examined parental coping and autism using an ethnographic approach with 33 parents whose children attended an autistic center in Australia. Coping strategies that were used by the parents in this study included: reliance on services provided by agencies (autism center, special schools); support of family members; religion (which gave a sense of meaning and purpose to the event of having a child with a disability); engaging in individually based strategies that either allowed them respite from their child’s condition or afforded them a sense of mastery and/or self worth; and limiting social activities that put the family in an uncomfortable position. With the exception of this ethnographic study, the literature on coping strategies of parents with autistic children is limited. There are, however, several studies that examine parental coping among children with other chronic disabilities such as congenital heart disease (Tak & McCubbin, 2002), Down Syndrome (Lam & Mackenzie, 2002), cystic fibrosis

(Hodgkinson & Lester, 2002), asthma (Brazil & Krueger, 2002) and attention deficit hyperactivity disorder (ADHD) (Podolski & Nigg, 2001).

Although studies examining the coping strategies of siblings of children with autism are limited, there is a related literature on siblings of children with disabilities or chronic illness. Most of the research focuses on the stressors faced by siblings of children with disabilities and only a few studies examine the coping strategies that these siblings employ. Cox et al. (2003) examined coping strategies used by 46 siblings of children with disabilities. Four coping strategies were identified: proactive responses which included problem solving and/or physical action; interactive responses which included seeking social support to manage the stressful situation; internally reactive responses which included expressing feelings of emotion or engaging in a cognitive response; and non-active responses in which the siblings did not demonstrate a physical or emotional response or denied a stressful situation.

Ryan (1989) studied the coping strategies of 103 school age children and found they used both cognitive and behavioral efforts to cope with stress. Ryan identified five categories of coping: social support (asking for help, talking with a parent); avoidant activities (trying to forget about the stress, ignoring it, doing something else); emotional behaviors (crying, getting mad); distracting behaviors (watching television, listening to music, cleaning room); and cognitive behaviors (planning what to do, thinking positively). Seltzer, et al. (2004) contend that research focused on the identifying

differences in coping among children with a sibling with autism and other comparison groups but does not provide a much needed explanation for those differences.

### **Family functioning.**

Family functioning encompasses the ways that family members interact with and relate to each other including the pursuit of goals, activities the family engages in together, and acceptance of family routines (Preechawong et al. 2007). The quality of the family relationship is paramount to the development of all children in a family (Leonard, 1991). When a family is functioning well, family members are less likely to develop psychological problems, are cohesive in their actions, are able to adapt to stressors, and have clear family rules and boundaries (Petrocelli et al. 2003).

Only a few studies examine family functioning when there is a child with autism in the family and mainly from the parent's perspective (Gallo & Szychlinski, 2003). Dyches et al. (2004) report that family adaptation and autism should be studied apart from other chronic disabilities as the issues of diagnosis, behavior challenges, and stigma are different from the issues that families with other disabilities face. Several studies indicate that family functioning is linked to the mental health of children (Connelly, 2005). Houtzager et al's. (2004) study of children 7-19 years of age who had a sibling with cancer found that a family systems approach to examining the impact a sibling's illness is essential. If the family is cohesive and is able to adapt to the stressors of having an ill child, then the siblings have fewer adjustment problems. On the other hand, more

adjustment problems are found in families that have poor interpersonal or family relations. The sibling's well being may also be impacted by the amount of distress that the parent displays.

### **Theoretical Framework**

The Resiliency Model of Family Stress, Adjustment and Adaptation guided this research study. The resiliency model of family stress, adjustment and adaptation has been investigated in relation to families who have children with chronic disabilities (Cox et al. 2003; Dyches et al. 2004; King et al. 2006; Snethen, Broome, Kelber, & Warady, 2004; Tak & McCubbin, 2002). This model views coping as a process that families engage in to respond to excessive demands, depleted resources, increased tensions, and to change the meaning of a situation (McCubbin, 1993; Tak & McCubbin). Inherent in this process is the fact that stressors, such as having a child with autism, requires that families make systemic changes to restore functional stability and improve family satisfaction.

There are several components in the family's adjustment to a stressor. The first component concerns the family's appraisal of the stressor which includes three levels of appraisal: 1) stressor appraisal, or the family's definition of the specific stressor; 2) situational appraisal, or the family's subjective definition of the demands they are experiencing as well as their resources and capabilities to manage the stressor; and 3) the global level of appraisal which takes into account the family's beliefs, values, and goals

(McCubbin, 1993). The family must define the seriousness of the stressor and the hardships the stressor will place on the family system.

The second component examines family resources that enable the family to manage the stressor to avoid a crisis in the family's pattern of functioning (McCubbin, 1993). Resources in the resiliency model include the characteristics, traits, or competencies that the family has or develops to manage the stressor. These resources may be found within the individual (intelligence, self esteem), the family system (cohesiveness, family organization), or the community (social support, health care services, respite).

The third component looks at the attributes that explain how the family system operates or behaves. The end result of the adjustment phase leads to family bonadjustment (when the family moves through a stressor with ease) or maladjustment and crisis (when established family patterns are disrupted). If the family is in the maladjustment phase of the model, the cycle of adaptation begins. During the adaptation phase, it is necessary to review the other demands facing the family. It is also necessary to assess both the individual and family strengths and coping strategies in order to determine the potential that the family has for meeting the demands placed on them. Adaptation is realized when the family is working as a unit with mutual support and shared goals, is interfacing with the community, and recognizes that, following a realistic appraisal of the stressor, compromise on some demands may be needed in order to promote adaptation.

The applicability of this theoretical framework for the adolescent population to the specific aims of the study is clear. The coping strategies that adolescents use most when contemplating their sibling with autism address that coping is seen as a process. The adolescent reflected on the relationship with their sibling with autism using the Sibling Relationship Scale which explores the adolescent's appraisal of the stressor thereby describing the seriousness of the stressor to the adolescent.

The self concept of the adolescent was examined as an individual resource that the adolescent possesses to manage living with a sibling with autism. The family system was also examined from the adolescent perspective when exploring their perception of family functioning. The Family Assessment Device has a cut off value that identifies healthy family functioning providing a way to evaluate the family's level of adaption from the adolescent perspective (see Appendix D).

## **Methods**

### **Measures.**

As a departure from prior work, this study does not use parent proxy. The measures for the study were selected based on their ability to be used in the adolescent population to obtaining information directly from the adolescent. Background information was obtained as well as information regarding caregiving activities and support group attendance (see Appendix A). The *Adolescent Coping Orientation for Problem Experiences* (A-COPE) (Patterson & McCubbin, 1987) was used to assess the coping

strategies that adolescents use. This 54 item questionnaire is comprised of 12 subscales; items in each subscale are summed to obtain the score for the subscale (see Appendix A). The *Family Assessment Device* (FAD)(Neabel et al. 2000) assesses family functioning on six dimensions; a general functioning scale using items that are not included in the six dimension subscales is also included. Cut-off scores for healthy family functioning are provided making the determination of what constitutes a healthy family less subjective (see Appendix A). Children's self-concept was assessed using the *Piers-Harris Children's Self-Concept Scale 2* (Piers & Herzberg, 2002). This measure has been used reliably with siblings of children with autism and other disabilities. A higher score indicates a higher self concept (see Appendix A). Level of satisfaction with the sibling relationship was measured using the *Satisfaction with the Sibling Relationship Scale* (McHale & Gamble, 1989). The original measure used a 9 point Likert scale which has been modified the scale to a 5 point scale in subsequent studies. For the purposes of this study, the 9 point scale was used. Scores for the measure are summed across dimensions with higher scores indicating more satisfaction with the sibling relationship (Appendix A). Qualitative questions were included to help inform interpretation of the quantitative data. The qualitative questions included inquiries about the challenges and positive experiences adolescents have had with their sibling with autism, how they handled the challenges, how the challenges or positive experiences made them feel about their sibling with autism, and how those challenges or positive experiences influenced themselves, their family, and their friends (see Appendix A).

### **Subject Recruitment.**

Approval for this study was obtained from the Institutional Review Board of the University of Michigan (IRB Health) and Western Michigan University. The adolescents were recruited via the Interactive Autism Network (IAN) community website with the assistance of their research coordinator who randomly sent cover emails to families who had adolescents that met the study inclusion criteria of: age 11-20 years; have a sibling with autism as diagnosed on the autism spectrum disorder; have sufficient command of the English language to respond to the survey (both reading and writing); and have access to a computer with internet access. Adolescents who had a history of developmental or language delays were excluded from the study (see Appendix B).

The online survey collection site, Survey Monkey, was used to collect data. Using computerized data collection has several advantages over pencil and paper questionnaires or face-to-face interviews including: avoidance of data entry errors; conditional branching embedded in the program; fewer incomplete responses; increased sense of confidentiality as there is no paper trail; and enhanced reporting of sensitive behaviors minimizing socially desirable responses (Mangunkusumo, Moorman, Van Den Berg-de Ruitter, Van Der Lei, De Koning, & Raat, 2005; Vereecken & Maes, 2006; Webb, Zimet, Fortenberry, & Blythe, 1999). Research suggests that adolescents are enthusiastic about using computerized questionnaires and rate the computerized interface highly (Mangunkusumo, et al; Vereecken & Maes; Webb et al). For the stated reasons, this method of data collection should appeal to the adolescent as well as facilitate the



achievement of the sample size as geographic distance is not a barrier and subjects from different geographic locations can easily access the study instruments.

### **Data Collection Procedures.**

Data were collected using Survey Monkey; all study instruments were loaded into Survey Monkey for ease of survey administration. Parent consent (see Appendix C) and adolescent assent (if 11-17 years old) (see Appendix C) and adolescent consent (if 18-20 years old (see Appendix C) were obtained prior to data collection. The IAN information for parents included a description of the study, the purpose of the study, eligibility criteria, risks, benefits, and study participants rights. After parents read the informed consent and agreed to allow their adolescent to participate, they were linked to the assent form for the adolescent to complete prior to beginning the survey. The adolescents also read an informed assent form prior to participating in the study. They, too, had a description of the study, purpose of the study, eligibility criteria, risks, benefits, and study participant rights. Submission of the measures implied consent/assent from the adolescent. Subjects completed the measures on a computer in a location that was comfortable for them as well as at a convenient time. Background information was collected for descriptive statistics and to help inform the interpretation of the analysis of the data. Completion of the measures took approximately 30-45 minutes. If needed, subjects could pause the survey at any time to take a break. A \$10 Amazon gift card was given as an incentive for completion. The participants were asked to provide their email

address in order to receive the incentive. A research assistant (RA) who had access to only the email addresses sent out the gift card. The RA did not have access to the data nor did the researcher view the email addresses of the participants.

Survey Monkey guarantees anonymity and the data are stored on a password protected computer thus ensuring confidentiality for the adolescent completing the survey. There will be no way for the researcher to link the parent or the adolescent's identity to the adolescent's responses. Following collection and analysis of the data, the data were stored on a computer disc in a locked drawer in the principal investigator's office.

The information in the following chapters will further explain the specific procedures, instruments and data analyses that were completed to examine the specific aims of this study.

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## **Chapter 1**

### **Coping with a Sibling with Autism**

The prevalence of autism is increasing at a rapid rate. This increase creates a burden not only on the healthcare system but also on families who are living with a child with autism. The literature on coping when there is a child with autism in the family is limited. Even less research has examined coping with having a sibling with autism from the adolescent perspective. Many of the studies that have examined coping with school age children and adolescents rely on parent proxy for obtaining the information. Parents are not always the best source for describing what children are feeling. Many children try to shield their parents from the struggles they are having knowing that their parents have worries of their own regarding the child with a disability (Gallo & Szychlinski, 2003; Guite, Lobato, Kao, & Plante, 2004; Hamama et al. 2000; Hayes, 1997; Sharpe & Rossiter, 2002). This study examined the coping strategies that adolescents use and whether males and females use different coping strategies. Further, it was hypothesized that older adolescents use more coping strategies than younger adolescents.

The Resiliency Model of Stress, Adjustment, and Adaptation (McCubbin, 1993) guided this research. This model has guided studies involving families of children with autism (Dyches, 2004; King, et al. 2006), siblings of children with disabilities (Cox, et al.

2003), families of children with congenital heart disease (Tak & McCubbin, 2002), adolescents with end stage renal disease (Snethen, et al. 2004), and adolescents in general (Patterson & McCubbin, 1987). The resiliency model of family stress, coping, and adaptation is consistent with the values and goals of nursing and provides a framework to examine the family's stress, coping, and level of adjustment.

## **Review of Literature**

### **Development of coping.**

Coping strategies are generally believed to develop during childhood and become more sophisticated as the child matures. However, children's coping strategies are not well understood or studied from a developmental perspective (Glasberg, 2000; Hamama, Ronen, and Feigin, 2000; Lerner & Benson, 2003; Ryan, 1989). There are several reasons for the difficulty in studying the development of coping. First, there is no clearly identified theory for examining coping in children or adolescents making it difficult to effectively use the theories from a developmental perspective (Ryan, 1989). Second, the majority of the studies that examine coping and children have not focused specifically on the development of coping strategies. Third, most of this literature refers to the stress and coping model and applies it to the child who has a disabled sibling without taking into account the child's developmental level (Houtzager et al. 2004).

As children mature cognitively and emotionally they are better able to problem solve and channel their emotions. Accordingly, the coping strategies that children use are

dependent on age and developmental level, as well. Skinner and Zimmer-Gembeck (2007) reviewed studies that examined age differences or changes in coping responses to stress. Transition periods for coping were identified including: late childhood to early adolescence (10-12); early and middle adolescence (12-16); and middle and late adolescence (16-22). Between the ages of 5-7 and 8-12 years, the most rapid development of coping occurred. During the younger years, coping is carried out by using direct action and enlisting the help of others as needed. This trend of seeking help from others continues as children move into adolescence.

As children reach middle childhood and their cognitive development progresses, they are able to use more sophisticated techniques for coping such as distraction, delay, and problem solving, either independently or with the guidance from others. By adolescence, children's cognitive development should be in formal operations enabling adolescents to more effectively problem solve and to regulate their coping responses and anticipate future implications of decisions. Adolescents are also able to determine which adults will be best able to help them in a given situation (Skinner & Zimmer-Gembeck, 2007).

Coping is also shaped by social relationships and contexts. Children's coping abilities develop in part by socialization and exposure to others who provide models of coping. Parents are also instrumental in role modeling both constructive and non constructive strategies for coping (Skinner & Zimmer-Gembeck, 2007; Zimmer-Gembeck & Locke, 2007). According to Ryan (1989) "both adaptive and maladaptive coping strategies are learned behaviors and can be acquired, changed, or eliminated" (p. 111). Further, parents

and other social supports may either be stressors themselves or may strive to buffer children from repeated stressors. Research is needed to examine how children's coping strategies shape their social relationships, as well as the impact that those coping strategies have on their development into adulthood (Clarke, 2006).

### **Coping with autism and chronic illness.**

Coping is a complex phenomenon that is not fully understood for the families of autistic children. Although a plethora of literature examines parental coping in a variety of pediatric populations, information specific to childhood autism is limited. Much of the research relies on the definition of coping set forth by Lazarus and Folkman (1984) who defined coping as the “constantly changing cognitive and behavioral efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 141).

Gray (1998) examined parental coping and autism using an ethnographic approach with 33 parents whose children attended an autism center in Australia. Coping strategies that were used by the parents in this study included: reliance on services provided by agencies (autism center, special schools); support of family members; religion (which gave a sense of meaning and purpose to the event of having a child with a disability); engaging in individually based strategies that either allowed them respite from their child’s condition or afforded them a sense of mastery and/or self worth; and limiting social activities that put the family in an uncomfortable position. With the exception of

this ethnographic study, the literature on coping strategies of parents with autistic children is limited. There are, however, several studies that examine parental coping among children with other chronic disabilities such as congenital heart disease (Tak & McCubbin, 2002), Down Syndrome (Lam & Mackenzie, 2002), cystic fibrosis (Hodgkinson & Lester, 2002), asthma (Brazil & Krueger, 2002) and attention deficit hyperactivity disorder (ADHD) (Podolski & Nigg, 2001).

Parents are not the only family members affected by living with a child with autism. The studies that examine the coping strategies of siblings of children with autism are limited. As with the review of literature on parents, it was necessary to review literature on siblings of children with disabilities or chronic illness in general. Most of the research has focused on the stressors faced by siblings of children with disabilities with only a few studies examining the coping strategies that these siblings employ. Cox et al. (2003) examined coping strategies used by 46 siblings of children with disabilities. Four general categories of coping strategies were identified: proactive responses which included problem solving and/or physical action; interactive responses which included seeking social support to manage the stressful situation; internally reactive responses which included expressing feelings of emotion or engaging in a cognitive response; and non-active responses in which the siblings did not demonstrate a physical or emotional response or denied a stressful situation.

Ryan (1989) studied the coping strategies of 103 school age children and found they used both cognitive and behavioral efforts to cope with stress. Ryan identified five

categories of coping: social support (asking for help, talking with a parent); avoidant activities (trying to forget about the stress, ignoring it, doing something else); emotional behaviors (crying, getting mad); distracting behaviors (watching television, listening to music, cleaning room); and cognitive behaviors (planning what to do, thinking positively). Seltzer et al. (2004) contend that research focused on the identification of differences in coping among children with autism and other comparison groups does not provide a much needed explanation for those differences. The purpose of the exploratory, correlational study reported here was to examine the coping strategies used by adolescent siblings of children with autism. The research questions addressed include: What coping strategies do adolescents who have a sibling with autism use as assessed by the Adolescent Coping Orientation for Problem Experiences (A-COPE)? Do adolescent males use different coping strategies than adolescent females when have a sibling with autism when measured using A-COPE? It was hypothesized that younger adolescents will use fewer coping strategies compared to older adolescents as measured by A-COPE.

## **Methods**

### **Design and Sample.**

An exploratory, correlational design using a convenience sample of 97 adolescents who are siblings of children with autism was recruited to examine the specific aims of the study. The study was designed to have a power of at least 80% with an alpha of .05 to detect a moderate (.30) correlation as described by Polit (1996).

Inclusion criteria included: age 11-20; have a sibling with autism as diagnosed on the autism spectrum disorder; have sufficient command of the English language (both reading and writing) to respond to the survey; and have access to a computer with internet access. Adolescents were excluded if they had a history of developmental or language delay.

### **Measures.**

The instruments used in the study were selected for their ability to be used in the adolescent population. The selected measures have been used in the adolescent population making it possible to obtain information directly from the adolescents rather than relying on parent proxy. In addition, these instruments are consistent with the concepts in the Resiliency Model of Stress, Adjustment, and Adaptation, the framework that guided this research.

### ***Background data.***

A background survey instrument was developed to collect demographic information from the adolescent. The background survey instrument also collected data regarding the age of sibling with autism, gender of sibling with autism, presence of other siblings in the family, and support group attendance (see Appendix A).



### ***Qualitative data.***

Qualitative data were collected to help inform interpretation of the quantitative data analysis. The adolescent was asked open ended questions on the survey. They were asked to describe challenges and positive things that they have encountered relating to their sibling with autism. For each of the challenges and positive items identified the adolescent was asked to describe the influence on themselves, their family, and friends. In addition, they were asked how they handled the challenges that were faced and how the described item made them feel about their sibling with autism. There were 85 respondents for each of the qualitative survey questions (see Appendix A).

### ***Adolescent Coping.***

The *Adolescent Coping Orientation for Problem Experiences (A-COPE)* (Patterson & McCubbin, 1987) assesses coping strategies used by adolescents 12-18 years of age. A-COPE focuses on the developmental needs of the adolescents in the areas of identity formation and independence from parents (Ryan-Wenger, 1994). While these are important developmental tasks for all adolescents, they may be even more important for adolescents who are trying to cope with a sibling with a diagnosis of autism. The focus on the family and the stress that they encounter when living with a child with autism, the use of the measure in well and ill adolescents, as well as the strong theoretical background for a family centered approach makes this instrument appropriate for use in a

study examining the coping strategies used by adolescents who have a sibling with autism.

The A-COPE questionnaire includes 54 questions and requires approximately 10 minutes for the adolescent to complete. The adolescent is asked “When you are faced with difficulties or feel tense how often do you...” The responses are based on a 5 point Likert scale (1 = Never, 2 = Hardly, 3 = Sometimes, 4 = Often, and 5 = Most of the time). Twelve subscales are obtained and are labeled: ventilating feelings (expression of frustration such as yelling), seeking diversions (efforts to keep busy to escape the stress), developing self-reliance and optimism (efforts to take charge of the situation), developing social support (efforts to stay emotionally connected), solving family problems (working out issues with family members), avoiding family problems (communicating feelings to family and following family rules), seeking spiritual support (praying or going to church), investing in close friends (seeking closeness and understanding from peers), seeking professional support (getting professional advice from counselor or teacher), engaging in demanding activities (becoming involved in challenging activities to excel at something), being humorous (making light of the situation), and relaxing (reducing tension through such activities as listening to music). Cronbach’s alpha reported in the literature ranged from .50 (seeking professional support) to .76 (investing in close friends) (Patterson & McCubbin, 1987) (see Appendix A).

Summing the scores for each item in the subscale gives a score for each of the subscales. Coping patterns that are used more frequently will have higher scores than

those used less frequently. A total score for the A-COPE can be calculated by summing the participant's responses for each item. Nine items (7, 8, 19, 24, 26, 28, 42, 46, and 49) need to be reverse scored so that all items are weighted in a positive direction (Snethen, et al. 2004).

## **Procedure**

### **Subject Recruitment.**

Approval for use of human subjects was obtained from the Institutional Review Board of the University of Michigan (IRBHealth) and Western Michigan University. Adolescents who have siblings with autism were recruited via the Interactive Autism Network (IAN) community web site ([www.ianproject.org](http://www.ianproject.org)). This web site allows researchers with proper permission from the Human Subjects Internal Review Board and written verification of status from the school of study to post research opportunities for families of children with autism. The research coordinator for IAN sent cover emails to parents of children with autism who are enrolled in IAN (see Appendix B). Initially, 713 emails regarding the research study were sent. Seventy-two adolescents completed the survey during a two month period. When responses slowed, the IAN research coordinator was contacted and 300 more emails regarding the research were sent resulting in ten more completed surveys. As a sample size of 92 was needed to have sufficient power, the survey was sent to 120 people resulting in six more completed surveys. A reminder email was sent to the final 120 people resulting in nine more completed surveys giving a total

of 97 participants and meeting the minimum of 92 participants. Parents of adolescents 11-17 needed to give consent (see Appendix C) for their adolescent to participate in the study as well as the adolescent giving their assent (see Appendix C) for participation. Adolescents who were over the age of 18 were able to give their own consent for participation in the study (see Appendix C). In the informed consent, parents were requested to allow their adolescent privacy while completing the questionnaires so that confidentiality for the adolescent can be maintained.

#### **Data Collection Procedures.**

Data collection was completed through the use of Survey Monkey. The instruments were loaded into Survey Monkey for ease of question administration. The IAN information for parents included a description of the study, the purpose of the study, eligibility criteria, risks, benefits, and rights of study participants. Parental consent was needed so that the adolescent could participate in the study. Once the parent had an opportunity to review the IAN letter and description of the study, they could connect to the link for the survey. After reading the informed consent and agreeing to allow their adolescent to participate, the parents were linked to the assent form for the adolescent to complete prior to beginning the survey. The adolescents also read an informed assent form prior to participating in the study. They, too, received a description of the study, purpose of the study, eligibility criteria, risks, benefits, and rights of being a study participant. Submission of the measures implied consent/assent from the adolescent. The

subjects completed the measures on a computer in a location that was comfortable for them as well as at a convenient time. Background and qualitative data were collected to help inform the interpretation of the data. Completion of the measures took approximately 30-45 minutes. Subjects could pause the survey at any time to take a break if one was needed. A \$10 Amazon gift card was given as an incentive for completion of the survey. The participants were asked to provide their email address and a research assistant (RA) had access to only the email addresses to send out the gift card. The RA did not have access to the data nor did the researcher view the email addresses of the participants.

Survey Monkey guarantees anonymity and the data were stored on a password protected computer thus ensuring confidentiality for the adolescent completing the survey. There was no way for the researcher to link the parent or the adolescent's identity to the adolescent's responses. Following collection and analysis of the data, the data were stored on a computer disc in a locked drawer in the principal investigator's office.

### **Data Analysis**

The data obtained from Survey Monkey were downloaded into SPSS 15.0 for data analysis. Prior to testing the research hypotheses and questions, a descriptive analysis of the data was completed. The demographic data of the sample were examined. Descriptive statistics for each A-COPE subscale as well as the total scale were calculated.

Frequencies and measures of central tendency were generated to determine which coping

strategies were used most often for adolescents who have a sibling with autism (Brink & Wood, 1998). An independent *t*-test was conducted to determine whether there was a difference in the coping strategies used by male and female adolescents who have a sibling with autism. An analysis of variance (ANOVA) was conducted to explore the differences in overall numbers of coping strategies used and the differences in the types of coping strategies used by early, middle, and late adolescent age groups. Bonferroni post hoc analysis was examined to determine the location of the differences in the adolescent age groups.

A constant comparative analysis was used to analyze the qualitative data. The qualitative data helped inform the interpretation of the quantitative data analysis. There were 85 responses for each of the open ended qualitative survey questions.

### **Sample Description.**

The sample consisted of 97 adolescents who have a sibling with autism and whose parent(s) are members of the Interactive Autism Network (IAN). The adolescents ranged in age from 11-19 years ( $M = 14.3$ ), were primarily Caucasian ( $n=85$ , 87.6%), and 82.5% ( $n=80$ ) had a brother with autism. This data supports the literature that more males than females are affected with autism (ASA, 2009). While it is believed that autism crosses all races, this sample of adolescents were primarily Caucasian (Rau, 2003). The sibling with autism ranged in age from 3-18 years with a mean age of 10.8 years. Gender of the adolescent sibling was not collected on the initial survey making it necessary for a

colleague to email the participants to determine gender, in addition to updating the survey with the gender information (n=53). Looking at the family constellation revealed that most respondents lived with their mother, father, and sibling with autism (see Appendix E).

## **Results**

To determine which coping strategies adolescents who have siblings with autism used most often according to A-COPE, descriptive statistics as well as frequencies, measures of central tendency, skew, and kurtosis were obtained for the 12 subscales: ventilating feelings, seeking diversions, developing self-reliance and optimism, developing social support, solving family problems, avoiding family problems, seeking spiritual support, investing in close friends, seeking professional support, engaging in demanding activities, being humorous, and relaxing (see Appendix E). The most frequently reported coping strategies subscale was seeking diversions and included items such as watching television, playing video games, sleeping, reading, and being involved in a hobby. The least frequently reported subscale was seeking professional support which included items such as talking with a teacher or counselor and getting professional counseling.

The reliability of the A-COPE scale as well as the subscales was also calculated. Cronbach's alpha for the entire scale was .85. Cronbach's alpha for the 12 subscales ranged from .31 (avoiding problems) to .81 (being humorous). Four of the 12 subscales, being humorous, seeking spiritual support, solving family problems, and engaging in demanding activity had  $\alpha > .70$  (see Appendix E). Cronbach's alpha did not increase for any of the subscales if any items were deleted. While acceptable reliability is generally .80, for psychological constructs, values  $< .70$  may be acceptable due to the variation in the constructs being measured (Kline, 1999 as cited in Fields).

An independent *t*-test was conducted for each of the A-COPE subscales to determine if there were differences in the coping strategies used by males and females in this sample. As gender was not collected on the initial survey, a total of 22 males and 31 females had gender data to use for the analysis. The power with the reduced sample was .81. Levene's test for equality of variances was examined prior to analyzing the *t*-test for each subscale (see Appendix E). Three of the subscales, developing social support, investing in close friends, and relaxing, showed a significant difference in coping strategies used between males and females. On average, females used the coping strategy developing social support ( $M = 19.17, SE = .766$ ) more than males ( $M = 16.62, SE = .942$ ). This difference was significant  $t(49) = -2.10, p < .05$ . The data for the subscale investing in friends also showed that on average, females invested in close friends ( $M = 5.90, SE = .413$ ) more than males ( $M = 4.71, SE = .317$ ). This difference was significant  $t(49.83) = -2.282, p < .05$  when equal variances are not assumed. The final subscale,



relaxing, showed on average that females ( $M = 13.40$ ,  $SE = .461$ ) used relaxing more than males ( $M = 11.82$ ,  $SE = .534$ ). This difference was also significant  $t(50) = -4.682$ ,  $p < .001$ . The remainder of the subscales and the overall A-COPE scale showed no significant differences in coping strategies used between males and females.

A one way analysis of variance (ANOVA) was used to determine if younger adolescents use fewer coping strategies compared to older adolescents. The transition periods for adolescents were identified by (Skinner & Zimmer-Gembeck, 2007) as late childhood to early adolescence (10-12 years), early to middle adolescence (12-16 years), and middle to late adolescence (16-22 years). As there was some overlap between early and middle and middle and late adolescence as defined by Skinner and Zimmer-Gembeck, for this study reported here, middle adolescence was designated as going through 16 years of age and late adolescence began at 17 years of age. There were 25 participants in the early adolescence group, 50 participants in the middle adolescence group, and 21 participants in the late adolescence group (see Appendix E).

The ANOVA revealed significant differences between age groups for five of the A-COPE subscales including developing social support, solving family problems, avoiding problems, being humorous, and relaxing, as well as for the total A-COPE scale. The Bonferroni post hoc comparison was significant for the five subscales and the A-COPE total scale. Developing social support was significant with early adolescent participants using this strategy more frequently than middle adolescence  $F(2, 80) = 3.64$ ,  $p = .05$ . Solving family problems also revealed a significant difference with early

adolescence using this coping strategy more frequently than middle adolescence  $F(2, 80) = 3.17, p < .05$ . The Bonferonni post hoc test also revealed a significant difference on the avoiding problems subscale. This difference was significant  $F(2, 80) = 5.06, p < .05$  between early adolescence and middle adolescence and between early adolescence and late adolescence. Being humorous was also significant  $F(2, 80) = 4.69, p < .05$  between middle and late adolescence age groups with the late adolescence group using humor more often. The subscale relaxing was significant  $F(2, 80) = 6.31, p < .05$  between the late adolescence group and both the early adolescence and middle adolescence age groups with the late adolescence group using relaxing more than the younger adolescence groups. Finally the entire A-COPE scale was examined for differences among the adolescent age groups. Bonferroni post hoc comparisons revealed that there were significant differences in the number of coping strategies used  $F(2, 80) = 4.61, p < .05$ , between the middle adolescence group and early adolescence and late adolescence groups with the early adolescence group using more coping strategies than the other two groups. The hypothesis that younger adolescents would use fewer coping strategies was not supported.

The qualitative results are included in the discussion section to enhance the interpretation of the quantitative results. Eighty-five adolescents responded to the qualitative open ended survey questions that were asked.

## **Discussion**

The results of this study facilitate understanding of coping strategies adolescents are using in response to having a sibling with autism. It was important to identify what the adolescents themselves were thinking and feeling rather than relying on parent proxy information as many studies have reported that parents are not always aware of the siblings' feelings (Gallo et al. 1991; Gallo & Szychlinski, 2003; Guite, Lobato, Kao, & Plante, 2004; Hamama et al. 2000; Hayes, 1997; Sharpe & Rossiter, 2002). The coping strategies that adolescents used were identified by use of the A-COPE instrument as well as qualitative data on how they handled the challenges of having a sibling with autism.

The most common coping strategy used by adolescents in this sample was seeking diversion. Items in this subscale included watching television, playing video games, sleeping, reading, and being involved in a hobby. Qualitative data were collected to help inform interpretation of the quantitative data. The participants were asked to tell about any problems they had growing up with a sibling with autism and how they handled those problems. Using a constant comparative analysis, diversion, consistent with the quantitative data, was one of the themes that emerged regarding how adolescents handled a problem. The respondents reported performing activities included in the seeking diversion subscale including reading, working on a hobby, playing on the computer, or watching television. These coping strategies differ from the strategies found by Cox et al. (2003) in a qualitative study of 46 6-18 year old siblings of children with disabilities. Cox et al. described siblings more frequently using proactive responses in a category of

problem solving or physical action in response to a stressor including such things as “deal with it” and “go to my room until I cool down” (p. 404). The qualitative data from the current study had similarities to Cox’s data with avoidance or ignoring sibling or behavior being reported by the respondents as helping them handling the challenges of having a sibling with autism.

Within this population of adolescents, the coping mechanism used least often according to A-COPE was seeking professional support including talking with a teacher or counselor and getting professional counseling. Ryan (1989) developed a taxonomy of coping strategies used by school age children based on a study with 103 children aged 8-12 years old. Consistent with the adolescent population in this study, no mention was made of talking with a teacher or getting professional counseling. This could be due in part to the definition of a coping strategy being something that you do when you feel “bad, nervous, or worried” (Ryan, 1989, p. 113). Unless a school aged child was already in counseling, using this as a strategy for what seem like normal trials in life might not have occurred to this younger age group. While there was not a direct question regarding the use of support groups on the A-COPE, the analysis of the background information regarding support group attendance indicates that talking with others is not a coping strategy used by many of the adolescents in the current study. The data revealed that 65% (n=63) of the adolescents did not know if there was a support group for siblings of children with autism in their area and 75% (n=73) had never attended a support group. Of

the seven adolescents who said they do attend support group meetings, two adolescents attend less than once per month and one attended 4 times per month.

Qualitative data from this study as well as from Cox et al. (2003) and Ryan (1989) revealed that while the adolescents are not talking with teachers or counselors, they are talking with parents about their concerns, with some reporting receiving help and support, while others felt talking with parents did not help much. One 13 year old in the current study reported,

“I told my parents my feelings and they apologized and explained why they had to pay more attention to him [sibling with autism] and promised to pay more attention to me. I am now mature enough to understand why they had to pay more attention to him and I don't mind at all anymore.”

Another 17 year old stated, “I talked with my parents about the difficulties, they helped me understand and suggested ideas to help.” Not all adolescents felt as supported when talking with their parents. One 14 year old reported “I usually try to talk to my mom but she is overprotective of him [sibling with autism] so she gets upset when I tell her anything bad about him.”

The reliability of the A-COPE subscales was disappointing, although not totally unexpected. Previous research using this instrument had internal reliability reported in many different populations including non Hispanic black and white junior and senior high school students (.60 for 5 of 12 subscales with no other data reported), adolescents with psychiatric disorders (.60 - .75), cystic fibrosis (.50 - .76), and end stage renal

disease (.44 - .81) (Finkelstein, Kubzansky, Capitman, & Goodman, 2007; Recklitis & Noam, 1999; Snethen et al., 2004). The subscale seeking diversion, which was the subscale used most frequently, had one of the lowest reliabilities ( $\alpha = .40$ ). While acceptable reliability is generally .80, for psychological constructs, values  $< .70$  may be acceptable due to the variation in the constructs being measured (Kline, 1999 as cited in Fields). The development of A-COPE was initiated when 30 10<sup>th</sup>, 11<sup>th</sup>, and 12<sup>th</sup> graders participated in a structured interview to identify coping behaviors that were used when they faced hardships. This led to the identification of 95 coping behaviors. Next, 467 11<sup>th</sup> and 12<sup>th</sup> graders completed the 95 item questionnaire to determine the factor structure (Patterson & McCubbin, 1987). While the instrument was designed for adolescents, 61% of the sample in the current study was younger than 10<sup>th</sup> grade which could have influenced their knowledge, experience, and understanding of some of the items included in the instrument.

When examining gender differences in coping strategy use, the adolescent females in this study used the coping strategies found in the subscales developing social support, investing in close friends, and relaxing more often than males. Items in the social support subscale included crying, helping others solve problems, keeping or making new friends, and talking with friends about feelings. The qualitative data revealed that adolescent females used crying as a coping strategy. One 14 year old female reported that she goes into her room and "...listens to music or get on the computer until I calm down. Other times I just lay on my bed and cry wondering what I did to deserve having a

brother with autism.” The influence on friends when a sibling has autism provided mixed results qualitatively. Keeping or making new friends in the developing social support subscale and investing in close friends are closely linked in the qualitative data.

Approximately half of the adolescents responding to this question indicated that having a sibling with autism did not impact their friendships or that their friends were understanding, accepting, and supportive. On the other hand, many adolescents stated their friends did not know they had a sibling with autism. One 14 year old female stated that her friends “...know just about nothing [about my sibling having autism], mostly because I do not talk to or see anyone except my family now.” An 18 year old female responded by saying “My brother acted as kind of a filter when it came to my friends. Friends that couldn’t handle or didn’t want to handle my brother’s autism didn’t stick around very long. My two best friends embrace him...”

Relaxing is the final subscale that demonstrated a statistically significant difference between males and females. The relaxing subscale consists of listening to music, eating food, riding around in the car, and daydreaming about how you would like things to be. Listening to music was cited in the qualitative data as a coping strategy that was used as were cooking and eating. The school age children in Cox et al.'s (2003) study also identified some relaxation activities such as deep breathing, staying calm, and resting. Although these relaxation activities are different than those asked about in A-COPE, educating adolescents about relaxation techniques could help all adolescents cope with any stressful situation, not just having a sibling with autism.

The hypothesis that younger adolescents would use fewer coping strategies was not supported in this sample. Skinner and Zimmer-Gembeck (2007) reported that coping is complex and that reviewing various coping strategies is difficult as instruments that measure coping mix “families” of coping strategies. As a result of mixing “families” of coping strategies, a problem solving approach in one instrument may not measure the same items in another instrument making it difficult to compare data on development of coping strategies across study populations. Skinner and Zimmer-Gembeck identified three significant transition periods in age for adolescent coping (10 – 12, 12-16, and 16-22 years). The ages of the adolescents in the sample were broken down into these age categories with the belief that older adolescents would use a more varied repertoire of coping strategies than younger adolescents. In reality, the youngest age group used more coping strategies followed by the oldest age group. This may be due in part to the fact that many siblings of children with disabilities take on more adult roles at much younger ages (Cox et al., 2003; Morgan, 1988). The qualitative data supports these findings. One adolescent reported that having a sibling with autism “...taught me independence because when my mom had to take my brother to therapy I would be able to be in the house alone and cook my own meals.” Another adolescent reported that “I have learned to do a lot of things like cooking and cleaning.” When examining the differences among adolescent age groups in this sample, one possibility is that the younger adolescents are trying a variety of coping strategies in an attempt to find strategies that work best for them. The middle adolescents used fewer coping strategies as they may have been able to refine the



strategies that work for them. The late adolescent group, who are more mature and have greater cognitive development, may be able to use different coping strategies for different situations increasing the number of coping strategies that they use.

The various subscales in A-COPE also were examined for age related differences. Skinner and Zimmer-Gembeck (2007) reported that older adolescents use more problem solving approaches than younger adolescents. Again, this was not found in the current sample in which the youngest adolescents used more problem solving approaches. This finding could be due in part to the items in the solving problem subscale which included some social support items such as talking with mother, father, or siblings which younger adolescents are more likely to do whereas older adolescents spend more time on average with peers. Skinner and Zimmer-Gembeck also found that when problem solving approaches were decreased in the older age groups, the items in the scale included social support seeking behaviors such as talking with parents or siblings meaning that in scales called problem solving there were social support items. The older adolescents were more likely to be optimistic about having a sibling with autism and more self reliant, future directed and independent in thinking through situations. Findings from previous research have found that as cognitive development matures, adolescents are able to use more sophisticated coping strategies (Cox et al. 2003; Skinner & Zimmer-Gembeck). Older adolescents also used relaxation, investing in friends, humor, and seeking diversion more frequently than the younger adolescent age groups which is consistent with their ability to take a ride in the car, go to a friend's house, drive to the movies, and have a perspective

on things that they can make light of a situation. Younger adolescents developed more social support than those in middle adolescence. It would seem that developing social support would include items such as spending time with friends and family. The social support subscale includes these items, but also includes crying, saying nice things to people, and apologizing. These emotion focused items are less likely to be used by older adolescents because as their cognitive development increases, they are better able to use cognitive strategies instead of emotion focused strategies (Skinner & Zimmer-Gembeck).

There are some limitations to this study. One limitation includes those related to sample gender data. Gender data were available for approximately 50% of the sample. Therefore, results on differences in coping strategy use by gender should be interpreted with caution. Cox et al. (2003) found that identified coping themes were not different for age or gender, while Ryan (1989) found gender differences in the coping strategies in a study of school age children. Another limitation was the numbers of participants in each of the age categories for adolescence. As there were few data on how many adolescents had siblings with autism, the age categories for early, middle, and late adolescence were not specifically recruited resulting in two times as many adolescents in the middle adolescent group than either the early or late adolescent groups. Future research could include a specific strategy to recruit equal numbers of adolescents in all age groups to examine if that would influence the frequency with which the coping strategies were used. A third limitation is that this was a convenience sample of adolescents who have parents that belong to the IAN which could mean that they receive support and advice on

interacting with siblings from other families who have children with autism and have assisted their adolescents to use a variety of coping strategies.

Another limitation is the low reliability of the A-COPE subscales. A larger sample would have enabled the researcher to do a factor analysis to examine if the factor structure should be adjusted. To do an accurate factor analysis, approximately 540 subjects would need to be recruited to have an accurate estimate of the factor structure. A future research project could examine a larger population of adolescents to re-examine the factor structure and subscale reliability.

This study contributes to an increased understanding of the coping strategies used by adolescents who have a sibling with autism. Nurses working with families who have children with autism need to be cognizant of the impact of autism on all family members including the adolescent sibling. Asking specific questions about the challenges that the adolescent is facing with their sibling with autism and how they are handling that challenge could begin a dialogue that would not only shed light on the coping strategies that the adolescent is using but could also be a starting point for interventions to help adolescents develop coping strategies that may work more effectively. Communicating with families together may help the adolescents and parents understand what each is feeling. This understanding can improve communication and strengthen family relationships. In addition, resources for either face-to-face or online support groups should be provided. This resource may be especially helpful for adolescents who identify that they do not interact with friends due to their sibling with autism. This resource could

also serve as a source of support for adolescents who feel they are not getting the attention from parents that their sibling with autism is receiving. Sharing with others and realizing that others are having the same feelings may not only help with the isolation some of these adolescents feel but may also connect the adolescent to new friends, either through face-to-face contact or through social networking sites, who can understand what they are experiencing.

## **Conclusions**

Adolescents use a variety of coping strategies to deal with the challenges of having a sibling with autism. Seeking diversion was the most frequently used strategy while seeking professional support from teachers or counselors was the least often used strategy. Females used the coping strategies developing social support, investing in close friends, and relaxing more often than male counterparts. The hypothesis that older adolescents would use more coping strategies than younger adolescents was not supported. This could be due to adolescents with siblings with autism having to grow up faster so they have a greater repertoire of coping strategies at a younger age. When examining the differences among adolescent age groups in this sample, one possibility is that the younger adolescents are trying a variety of coping strategies in an attempt to find strategies that work best for them. The middle adolescents used fewer coping strategies as they may have been able to refine the strategies that work for them. The late adolescent group, who are more mature and have greater cognitive development, may be able to use

different coping strategies for different situations increasing the number of coping strategies that they use. Future research will examine more closely the qualitative data in relation to the challenges that adolescents who have a sibling with autism face and the strategies that they use to cope with those challenges. In addition, the qualitative data will be analyzed examining age and gender to see if this sheds light on developmental levels of coping that were not captured in the A-COPE instrument.

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## **Chapter 2**

### **Adolescent Perception of Family Functioning**

Family functioning is an important concept to consider in examining siblings in families with a child with a chronic illness or condition. Family functioning encompasses the ways that family members interact with and relate to each other including the pursuit of goals, activities the family engages in together, and acceptance of family routines (Preechawong et al. 2007). The quality of the family relationship is paramount to the development of all children in a family (Leonard, 1991). When a family is functioning well, it has been found that family members are less likely to develop psychological problems, are cohesive in their actions, are able to adapt to stressors, and have clear and explicit family rules and boundaries (Petrocelli et al. 2003).

Few studies address family functioning when there is a child with autism in the family. In addition, studies that examine family functioning do so mainly from the parents' perspective (Gallo & Szychlinski, 2003). The purpose of this exploratory, correlational study was to examine the perceptions of their family functioning among adolescents with a sibling with autism. The research questions included: How do adolescents who have a sibling with autism perceive that their family is functioning as measured by the Family Assessment Device (FAD)? Do perceptions of family function differ by age and gender when measured with the FAD?

The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin, 1993) was the framework that guided this research study. The resiliency model of family stress, adjustment and adaptation has been investigated in relation to families who have children with chronic disabilities (Cox, et al. 2003; Dyches et al. 2004; King et al. 2006; Snethen et al. 2004; Tak & McCubbin, 2002). In this model, coping is seen as a process that families engage in to respond to excessive demands, depleted resources, increased tensions, and to change the meaning of a situation (McCubbin, 1993; Tak & McCubbin). Inherent in this process is the dynamic that stressors, such as having a child with autism, requires that families make systemic changes to restore functional stability and improve family satisfaction. For the study reported here, the resiliency model was specified to include the coping strategies that adolescents use when having a sibling with autism to examine how these coping strategies influence the adolescent perception of family functioning. The resiliency model includes the resources that the individual or family bring to the situation. For an adolescent with a sibling with autism, one resource that the adolescent possesses is self-concept. Finally, the meaning that one attaches to the stressor needs to be examined. For this study, examining how satisfied the adolescent is with the sibling relationship will be explored as it relates to the coping strategies that are used and the adolescent perception of family functioning. The goal of the resiliency model is to facilitate family adaption which will be operationalized in this study as the adolescent's perception of healthy family functioning (see Appendix D).

## **Review of Literature**

All families face the task of trying to have healthy family functioning. Family functioning is defined as the way that family members relate to each other and work together to accomplish critical tasks (Preechawong, et al. 2007). Family functioning includes adjustment, adaptation, and cohesion. Adjustment occurs when families are able to balance the stressor with coping strategies and problem solving to reduce family vulnerability and improve family functioning. Adaptation results when families are able to make adjustments in their coping and problem solving strategies to lessen the burden of the demands that are placed on the family. Adaptation also takes into account the resources that individual and family members possess as well as the meaning that the stressor has for individual family members in addition to the family as a whole (Dyches, et al. 2004). Family cohesion includes the closeness and involvement that family members have with one another (Houtzager, et al. 2004).

Family functioning is an important concept to consider, especially of parents and siblings in families with a child with a chronic illness. A number of studies have examined family functioning within the context of children with disabilities. Dyches et al. (2004) recommend that families with a child with autism should be studied separately from families with children with other chronic disabilities as the issues of diagnosis, behavior challenges, and stigma are different. Houtzager et al. (2004) studied children 7-19 years of age who had a sibling with cancer and reported that a family systems approach when exploring the influence of having a sibling with an illness is important as

changes in one family member influences other family members. If the family is cohesive and is able to adapt to the stressors of having an ill child, then the siblings have been found to have fewer adjustment problems. On the other hand, more adjustment problems are found in families that have poor interpersonal or family relations. Families that had a family structure that provided stability were more balanced and had healthier family functioning (Houtzager et al. 2004).

Roelofse and Middleton (1985) outline six dimensions of family functioning that should be explored. The first dimension is structure. Families need to have clear boundaries that are permeable with a parent subsystem that works together. The second dimension, affect, necessitates a range of affective responses. The third dimension is direct communication that is understood by all members. Fourth, behavior control is when a family makes decisions in a democratic manner. The fifth dimension, value transmission, is the way the values and morals are passed on in the family. Finally, the sixth dimension, external systems examines relationships with systems outside the family unit. This dimension, coupled with structure, necessitates that the family system has permeable boundaries. It is important to examine these dimensions to determine areas that are strengths and weaknesses for families so that interventions can be tailored to improve family functioning.

The literature on family functioning related to siblings of children with autism is limited. Research examining family functioning and autism typically reflects the parent's perspective. Hutton and Caron (2005) explored with 21 parents their experiences of

having children with autism. One question asked of the parents was the affect on the siblings of the child with autism. Parents reported that the sibling of the child with autism felt jealousy and resentment toward their sibling, feeling that their siblings received more attention than they did. Parents also stated that siblings were sad for and fearful of their sibling with autism. Normal family outings were stressful and impromptu activities did not occur as much planning had to take place so that the child with autism did not have outbursts or was the recipient of stigma from others.

There are many studies that address family functioning in families who have children with chronic illnesses yet most of these studies examine family functioning from the parent perspective. As there is little known about family functioning in families who have children with autism and even less is known about family functioning from the adolescent perspective, this research study will provide a better understanding about the experiences of living in a family with autism from the adolescent perspective.

## **Methods**

### **Design and Sample.**

An exploratory, correlational design was used for this study. A convenience sample of 97 adolescents who are siblings of children with autism was recruited to achieve the specific aims of the study. The study was designed to have a power of at least 80% with an alpha of .05 to detect a moderate (.30) correlation as described by Polit (1996). Inclusion criteria included: age 11-20 years; have a sibling with autism as

diagnosed on the autism spectrum disorder; have sufficient command of the English language (both reading and writing) to respond to the survey; and have access to a computer with internet access. Adolescents were excluded if they had a history of developmental or language delay.

### **Measures.**

The measures used in the study were selected for their ability to operationalize the central concepts for the study and to be used with the adolescent population. The selected measures have been used with the adolescent population making it possible to obtain information directly from the adolescents rather than relying on parent proxy. In addition, A-COPE is an instrument based on the concepts in the Resiliency Model of Stress, Adjustment, and Adaptation, the framework that guided this research.

### ***Background data.***

A background survey instrument was developed to collect demographic information from the adolescent. The background survey instrument also collected data regarding the age of sibling with autism, gender of sibling with autism, presence of other siblings in the family, and support group attendance. The background information was loaded into the Survey Monkey database along with the other measures to be completed (see Appendix A).

### ***Qualitative data.***

Qualitative data were collected to help inform interpretation of the quantitative data analysis. The adolescent was asked open ended questions on the survey. They were asked to describe challenges and positive things that they have encountered relating to their sibling with autism. For each of the challenges and positive items identified the adolescent was asked to describe the influence on themselves, their family, and friends. In addition, they were asked how they handled the challenges that were faced and how the described item made them feel about their sibling with autism. There were 85 respondents for each of the qualitative survey questions (see Appendix A).

### ***Family Functioning.***

The *Family Assessment Device* (FAD) is a 60 item instrument that takes approximately 15-20 minutes to complete (Neabel, Fothergill-Bourbonnais, & Dunning, 2000). The FAD assesses family functioning on six dimensions: problem solving, which assesses the ability of the family to resolve problems together; communication, which examines the effectiveness of the communication in the family; roles, which examines how family tasks are assigned and if those tasks are completed; affective responsiveness, which addresses the ability of the family members to respond to situations with appropriate emotions; affective involvement, which looks at the degree of interest that is shown in other family member's lives; and behavior control, which describes the expectations for behavior. In addition, the instrument has a general functioning subscale



that assesses the overall health of the family. The general functioning subscale is an independent scale that does not include items from the previously mentioned subscales (see Appendix A). Cronbach's alpha for the subscales range from .72 - .92 (Epstein, et al. 1983; Neabel et al. 2000; Petrocelli et al. 2003; Tamplin & Goodyer, 2001).

Responses to items in the FAD use a Likert scale that ranges from 1 strongly disagree to 4 strongly agree. A subscale score is obtained by reverse scoring the negatively directed items, summing the item scores and then weighting the scores for each subscale by dividing the score by the number of items in the subscale. Scores for each subscale are averaged with higher scores indicating less healthy functioning. Cut off values for healthy and unhealthy families have been established for each subscale and range from 1.9 (behavior control) to 2.3 (roles). These cut off values have acceptable sensitivity, specificity, and positive predictive value (Neabel et al. 2000). Tamplin and Goodyer (2001) examined 253 adolescents at risk for psychopathology. In a sample of families from the United Kingdom, unhealthy families were identified if their family mean scores exceeded the established cut offs on four or more of the subscales. Both adolescents and their parents completed the FAD in the Tamplin and Goodyer study. Adolescents reported their family functioning as significantly worse than their parents on all scales except the roles scale. In addition, the lower the adolescent's mood and self esteem, the lower their family functioning score. One limitation to the FAD is that the scores can be distorted due to the subject's mood which was not controlled for in the current study (Tamplin & Goodyer, 2001).

The feasibility and utility of the FAD is evident for the adolescent population. The reading level is at 6<sup>th</sup> grade which is an appropriate reading level for adults and adolescents (Redman, 2001). The instrument has been used with a variety of populations and cultures with consistent reliability. The cut off values for the subscales help the nurse to identify areas in which families may need assistance and enabling the nurse to provide interventions to improve the health of the family.

## **Procedure**

### **Subject Recruitment.**

Approval for use of human subjects was obtained from the Institutional Review Board of the University of Michigan (IRBHealth) and Western Michigan University. Adolescents who have siblings with autism were recruited via the Interactive Autism Network (IAN) community web site ([www.ianproject.org](http://www.ianproject.org)). This web site for parents of children with autism allows researchers, with proper permission from the Human Subjects Internal Review Board and written verification of status from the school of study, to post research opportunities for families of children with autism. The research coordinator for IAN sent cover emails to parents of children with autism who are enrolled in IAN (see Appendix B). Initially, emails were sent to 713 families who had adolescents who met the inclusion criteria. Seventy-two adolescents completed the survey during a two month period. When responses slowed, the IAN research coordinator was contacted and 300 more emails regarding the research were sent resulting in ten more completed

surveys. As a sample size of 92 was needed to have sufficient power, the survey was sent to 120 people resulting in six more completed surveys. A reminder email was sent to the final 120 people resulting in nine more completed surveys giving a total of 97 participants. Parents of adolescents 11-17 needed to give consent for their adolescent to participate in the study (see Appendix C). The adolescent also gave their assent for participation (see Appendix C). Adolescents who were over the age of 18 were able to give their own consent for participation in the study (see Appendix C). In the informed consent, parents were requested to allow their adolescent privacy while completing the questionnaires so that confidentiality for the adolescent could be maintained.

#### **Data Collection Procedures.**

Data collection was completed through the use of Survey Monkey. The instruments were loaded into Survey Monkey for ease of answering the questions. The IAN information for parents included a description of the study, the purpose of the study, eligibility criteria, risks, benefits, and rights of being a study participant. Parental consent was needed so that the adolescent could participate in the study. Once the parent had an opportunity to review the IAN letter and description of the study, they could connect to the link for the survey. After reading the informed consent and agreeing to allow their adolescent to participate, the parents were linked to the assent form for the adolescent to complete prior to beginning the survey. The adolescents also read an informed assent form prior to participating in the study. They, too, received a description of the study,

purpose of the study, eligibility criteria, risks, benefits, and rights of being a study participant that was written at their level of understanding. Submission of the measures implied consent/assent from the adolescent. The subjects completed the measures on a computer in a location that was comfortable for them as well as at a time that was convenient for them. Background information was collected to help inform the quantitative portion of the data. Completion of the measures took approximately 30-45 minutes. The adolescents could pause the survey to take a break at any time if one was needed. A \$10 Amazon gift card was given as an incentive for completion of the survey. In order to receive gift card, the participants needed to provide their email address and a research assistant (RA) that had access only to the email addresses sent out the gift card. The RA did not have access to the data nor did the researcher view the email addresses of the participants.

Survey Monkey guarantees anonymity and the data were stored on a password protected computer thus ensuring confidentiality for the adolescent completing the survey. There was no way for the researcher to link the parent or the adolescent's identity to the adolescent's responses. Following collection and analysis of the data, the data were stored on a computer disc in a locked drawer in the principal investigator's office.

### **Data Analysis**

The data obtained from Survey Monkey were downloaded into SPSS 15.0 for data analysis. Prior to testing the research hypotheses and questions, descriptive analyses of

the data were completed. The demographic data of the population were examined. Descriptive statistics for the subscales as well as the general functioning scale were used to describe how adolescents who have a sibling with autism perceive that their family is functioning according to FAD (Brink & Wood, 1998). A MANOVA using SPSS 15.0 was completed to explore the differences in perception of family functioning by gender and by early, middle, and late adolescent age groups. A Hotelling's T was used as a post hoc analysis to determine the location of differences among the variables being examined.

A constant comparative analysis was used to analyze the qualitative data. The qualitative data helped inform the interpretation of the quantitative data analysis. There were 85 responses for each of the open ended qualitative survey questions.

### **Sample Description.**

The sample consisted of 97 adolescents who have a sibling with autism and whose parent(s) are members of the Interactive Autism Network (IAN). The adolescents ranged in age from 11-19 years, were primarily Caucasian (n=85, 87.6%), and 82.5% (n=80) had a brother with autism. These data support the literature that more males than females are affected with autism (ASA, 2009). The sibling with autism ranged in age from 3-18 years. Gender of the adolescent sibling was not collected on the initial survey making it necessary for a colleague to email the participants to determine gender and update the survey with this information (n=53). More than half of the adolescent siblings

had other siblings in addition to the sibling with autism. Looking at the family constellation revealed that most respondents lived with their mother, father, and sibling with autism (see Appendix E).

## **Results**

To determine how adolescents perceived that their family is functioning, descriptive statistics as well as measures of central tendency, skew, and kurtosis were examined for the FAD subscales including: problem solving, communication, roles, affective responsiveness, affective involvement, behavioral control, and general family functioning. The FAD has acceptable reliabilities ranging from .77 (roles and behavioral control subscales) to .90 (general functioning subscale) (see Appendix E).

The FAD has established cut points for healthy family functioning ranging from 1.90 (behavioral control) to 2.30 (roles) based on the subscales means. The means for each subscale were calculated. Means that are higher than the established cut points indicate unhealthy family functioning. Five of the seven subscales (affective involvement, problem solving, communication, roles, and general functioning) revealed that the adolescents in this sample perceived that their families were functioning in the unhealthy range (see Appendix E).

A multivariate analysis of variance (MANOVA) was completed to determine if there were any differences between gender and adolescent age groups on the general family functioning scale of the FAD. No differences were found on family functioning

when examining age and gender. Using Hotelling's T, there were no significant effects on family functioning related to age or gender,  $T = .65$ ,  $F(14, 68) = 1.60$ ,  $p > .05$ .

## **Discussion**

Little is known about how families function when there is a child with autism in the family. Studies that examine family functioning, specifically with siblings, use a variety of measures making it difficult to compare and generalize across studies and different samples. This study serves as a beginning step in examining, from the adolescent's perspective, how they perceive that their family is functioning. The FAD has acceptable reliability (.77-.90) for all subscales which is consistent with previous research using the FAD (Epstein, et al. 1983; Neabel et al. 2000; Petrocelli et al. 2003; Tamplin & Goodyer, 2001). Using the cut off scores for healthy family functioning is a subjective way to measure how a family is performing as a group. Five of the seven subscales (affective involvement, problem solving, communication, roles, and general functioning) were above the cut off scores indicating unhealthy family functioning. Although the scores for this sample of participants scored above the cut off scores, their scores tended to cluster around the threshold scores. It is still important to examine each of the areas that are above the cut off scores to determine if interventions can be designed and implemented to improve the functioning of not just the adolescent but the entire family. Assessing the areas that are in the healthy functioning range provide a platform from which to build on the perceived strengths of the family.

Affective involvement is the subscale that demonstrated the greatest difference from the cut score. The items in this subscale included: family members are only interested in me if they get something out of it, intrude in each other's lives, get too involved if there is trouble in the family, and family members are too self-centered (Epstein, et al. 1983). The qualitative data revealed that affective involvement does pose a problem for adolescents in this study. One adolescent, when talking about her brother with autism and her family, reported,

I watch him until my mom gets home....Tantrums are getting worse and when he has a tantrum my mom gets crabby so if I do something wrong she snaps at me. It makes me really sad when I hear her dealing with him and sometimes I start to cry because I think of how much pain he causes our family and how much time we take out of our lives for him but he is still so ungrateful.

This adolescent not only sees her brother as self-centered, but she has little reward for assisting in his care.

Problem solving also had results that were above the cut-off scores for healthy family functioning. Items in this scale include resolving emotional upsets, resolving problems around the house, and confront problems involving feelings. Previous work confirms that parent proxy is not the best method to obtain information about how siblings are feeling regarding a sibling with a chronic illness (Guite, Lobato, Kao, & Plante, 2004 and Hamama et al. 2000). Consequently, it is not surprising that adolescents who have a sibling with autism did not divulge their feelings to their parents. The



qualitative data revealed that only eight of the 85 participants report they talk with their parents about difficulties with their sibling with autism. There were others who said they get angry and walk away from situations, others who reported feeling stress and tension not only in them but in the entire family, and several adolescents who were resigned to the way their family handled challenges with the sibling with autism. One adolescent reported “My mom would get annoyed and stressed out. I would get sad but I didn’t want to give my mom any more trouble than she was already dealing with so I kept to myself.” This adolescent avoided confronting problems involving feelings to protect her mother. Encouraging families to talk about their feelings and how they can work together to resolve problems would not only strengthen the family but would give the adolescent a model for dealing with feelings and problems in their daily life.

Communication is closely linked to problem solving in that effective problem solving many times relies on clear, direct, nonemotion driven communication. Healthy forms of communication as identified on FAD include such items as: say things instead of hinting, talk directly to person rather than use a go between, and when someone is upset, others know. Unhealthy forms of communication according to FAD include such items as: family members “often don’t say what they mean,” “can’t tell feelings from what is said,” and “don’t talk when angry.” The qualitative data provided adolescents’ perceptions about communication challenges and successes. Adolescents expressed frustration with not being able to understand their sibling with autism making it difficult to be satisfied with the communication pattern with their sibling. Other adolescents

reported that they go to their room when they are mad or upset. One adolescent stated “I try to step away from the situation when my brother has his meltdowns. I also like to leave the house when everyone is frustrated.” When an adolescent leaves the house rather than discussing the feelings of frustration healthy communication is avoided. Other adolescents are able to talk with their parents about their difficulties and said “they helped me understand and suggested ideas to help.” The conversations that engage family members in active problem solving to reach mutual goals benefit the entire family. It would be beneficial to all family members to learn communication techniques that would enhance family communication to promote healthier family functioning.

Roles is another subscale that demonstrated unhealthy family functioning. Healthy roles include items such as: members meet family responsibilities and each has duties and responsibilities and unhealthy roles include items such as family tasks “don’t get spread around,” “trouble paying bills,” “dissatisfied with assigned duties,” and “there is little time for personal interests.” The results related to roles are consistent with research findings that siblings of children with disabilities take on more caretaking roles in addition to normal household tasks (Leonard, 1991; McHale & Gamble, 1987). The qualitative analysis also revealed that adolescents have caretaking roles in the family including “babysitting more than a normal family has too. I often have to give up plans with friends to take care of my brother with autism.” Having to give up plans with friends when you are an adolescent can contribute to the adolescent feeling like there is little time for personal interest. Another adolescent talked about caring for a brother who “is

very dependent on us to help him eat, bathe, dress, and toilet. Caring for him and cleaning up after him are daily tasks.” In contrast, some adolescents found caring for their sibling with autism a positive experience. One adolescent described the benefits of taking on household tasks. “It taught me independence because when my mom had to take my brother to therapy I would be able to be in the house alone and cook my own meals.”

Adolescents identified financial concerns in the qualitative portion of the survey. Two adolescents identified that their mothers no longer worked. This resulted in limited financial resources for presents or doing activities as a family. One adolescent reported “I’ve missed opportunities in life because I have a sister with autism. We spend the majority of our money on things for her.” Another adolescent echoed that “mom no longer works and my stepdad has almost no money left over from paying for my brother’s therapy and his medicine, etc.” The change in parental employment and less expendable income is consistent with other findings in studies with families and autism. Grey (2002) conducted a longitudinal study with families of children with autism and reported that mothers often delayed or gave up their career goals to care for their child with autism. Ten years after the initial study, many mothers still were not able to work but a few mothers had gone back for further schooling or were working. The father’s employment is not as influenced by having a child with autism unless relocating is necessary to be near an autism treatment facility or school. This scenario was described by one adolescent who said, “Had to move to other places to get more resources or send

my brother to new schools.” These examples demonstrate the myriad of ways that autism affects a family.

The finding on the general functioning scale of the FAD also documents unhealthy family functioning. Items on the general functioning scale that indicate healthy functioning include such items as: in a crisis we turn to each other for support; confide in each other; accepted for what and who you are; and can express feelings to each other. Items that constitute unhealthy functioning include such items as: we don’t get along well together; family misunderstands each other; and can’t talk with each other regarding sadness. Adolescents at high and low risk for depression also scored above the cut score for the general functioning scale while the parents scores were below the cut scores (Tamplin & Goodyer, 2001). Although Roelofse and Middleton (1985) used The Family Functioning in Adolescence Questionnaire (FFAQ), which measures family functioning focusing on the developmental tasks of the adolescent, it includes many general functioning subscale FAD items. The healthy adolescents who participated in the development of this questionnaire viewed their families positively overall. In the current study, challenges to family functioning were revealed in the qualitative data. Adolescents report that they are not able to go places as a family or do things spontaneously and that there is stress in their family and that family members do not always get along. Although the qualitative data did reveal challenges to family functioning, there were positive family functioning statements. Some of the sample reported that their sibling with autism was a blessing, made us stronger, or drew us closer as a family. One adolescent stated

“we are so much closer than most families... We know we can get through anything together and I want to be close with my family.” Another adolescent reported “It has made us closer because we were going through it together. No one else knows what it is like unless they live with it.” This last statement is poignant as this is the very reason it is important to explore with these adolescents what is it like to have a sibling with autism.

In summary, the adolescents in this study perceived that their family functioning was unhealthy for the following subscales: affective involvement; problem solving; communication; roles; and the general functioning scale. Adolescents perceived that their family functioned in the healthy range for affective responses and behavior control. The qualitative data supported the findings from the FAD regarding the adolescent’s perception of family functioning. Adolescents report that they do not communicate their feelings with their parents and walk away from situations rather talk about how they are feeling. Many adolescents reported having to give up or change plans because of their sibling with autism. Other adolescents described feelings of independence as a result of having to cook and clean while their parents were busy with their sibling with autism. Neither age nor gender influenced the perception of family functioning.

There are limitations in this study. There was no control group of siblings without autism or other chronic disorders to see if perception of family functioning is similar across all adolescents. Tamplin and Goodyer (2001) used the FAD to examine adolescents who were at low or high risk for a major depressive disorder. Adolescents in Tamplin and Goodyer’s study, regardless of their risk for depression, scored higher than

the cut off scores on all subscales including the general functioning scale leading one to believe that all adolescents might perceive that their family doesn't function in a healthy manner. Another limitation is that this was a convenience sample of adolescents who have parents that belong to the IAN, which could mean that they receive support and advice on interacting with siblings from other families who have children with autism and have made accommodations in their family. A third limitation involved collecting gender information from the adolescents. Gender data were available for approximately 50% of the sample. Another limitation was the numbers of participants in each of the age categories for adolescence. As there was little data on how many adolescents had siblings with autism, the age categories for early, middle, and late adolescence were not specifically recruited resulting in two times as many adolescents in the middle adolescent group than either the early or late adolescent groups. Future research could include recruiting equal numbers of adolescents in all age groups to examine if that would influence the perception of family functioning.

While much was learned from the study, it serves as a beginning step in understanding families of children with autism. Future research could include having parents and adolescents complete the FAD to see if there are different perspectives on how the family functions. In addition, it would be helpful to recruit adolescents who have siblings without disabilities to see how they perceive that their family is functioning and compare the results to adolescents who have siblings with autism.

## **Conclusions**

The adolescents' perception of family functioning was unhealthy for five of the seven scales on the FAD while two subscales were in the healthy range. Neither age nor gender influenced the adolescent's perception of family functioning. Future research will examine family functioning from both the parent's and adolescent's perspective to determine if there are similarities of scores above those identified for healthy family functioning. Further analysis of the qualitative data will be completed to explore whether gender or age differences in perception of family functioning are identified.

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### **Chapter 3**

#### **Relationship of Coping, Family Functioning, Self-Concept, and Satisfaction with Sibling Relationship**

Autism is a complex disorder and affects all family members and many aspects of family life. Many studies have been completed that explore the etiology of autism and issues that parents face when they have a child with autism, but few studies examine the experiences of siblings of a child with autism. The proposed model (see Appendix D) explores the relationship among the variables of coping strategies, perception of family functioning, self-concept, satisfaction with the sibling relationship, age, and gender for adolescents who have siblings with autism. The Resiliency Model of Stress, Adjustment, and Adaptation guided this research study (McCubbin, 1993) (see Appendix D). This model enables the researcher to examine the family as a whole or from the perspective of the individual, taking into account the individual's perception of the stressor and the resources such as self concept that the individual brings to the stressor. The specific aim of this study was to determine the predictive ability of the proposed model. The research question is how are the variables of coping strategies, perception of family functioning, self concept, and satisfaction with the sibling relationship, taking into account age and gender, related for adolescents who have siblings with autism?

## **Review of Literature**

Coping is a complex phenomenon. There are individual and social support characteristics that determine the coping strategies that an individual uses in response to a stressor. Individual characteristics include age, gender, coping skills, and self esteem while the social network characteristics include social support and family functioning (Charron-Prochownik, 2002). Research regarding the impact that coping has on family functioning is inconsistent. Higgins, Bailey, and Pearce (2005) studied primary caregivers of children with autism to examine the relationships among the characteristics of autism that the child displayed, family functioning, and coping strategies. The authors hypothesized that style of coping would add to the prediction of adjustment (which included marital happiness, family adaptability, family cohesion, and self-esteem). Using multiple regression, they found that the relationship between coping style and family adjustment were unrelated (Higgins, Bailey, & Pearce, 2005). Preechawong et al. (2007), on the other hand, found that family functioning influenced resourceful coping in Thai adolescents with asthma. These studies underscore the lack of concrete knowledge about the relationship between coping and family functioning in general, but particularly in relation to adolescents who have siblings with autism.

The dynamics of any family are complex and the sibling relationship is no exception. If there is one child in the family who is favored over another or if there are sibling relationships that are in constant conflict, family functioning and the sibling's adjustment and psychological well being are at stake (Richmond & Stocker, 2006). To

understand how having a sibling with autism impacts the life of the adolescent, it is necessary to examine the influence of the sibling relationship. Therefore, the purpose of the study reported here was to explore the relationships among coping strategies, self concept, satisfaction with the sibling relationship, age, gender, and family functioning.

The longevity of the sibling relationship is unparalleled in any other relationship. These longitudinal relationships influence many aspects of development including the cognitive, affective, and social skills as well as the development of a positive self concept of the siblings. The sibling relationship makes it possible to express feelings and to experience friendships, loyalty, rivalry and support (Harris & Glasberg, 2003; Higgins et al. 2005; Verté et al. 2003). The sibling relationship influences a child's socialization. It is in this relationship that children learn new roles of teacher, caregiver or leader for younger or less capable siblings (McHale & Gamble, 1987). With the changing structure of the family, the sibling relationship is even more important. Siblings are relying more on each other as the proportion of single parent families, as well as of dual wage earner families is increasing (Morrison, 1997).

Children with disabilities are surviving longer and are more likely to receive care in the home rather than in an institution. This increases the likelihood that siblings will be impacted by living each day with a sibling with a disability (Cox, et al. 2003). The care that children with autism need is ongoing. As parents age, the sibling becomes a likely source of care for the child with autism which can cause anxiety in the adolescent who is

able to look toward the future and see potential caregiving responsibilities (Harris & Glasberg, 2003).

Sharpe and Rossiter (2002), using a meta-analysis of siblings of children with chronic illness, concluded that more methodologically sophisticated studies of siblings of children with disabilities are needed. For example, many studies rely on parent report despite the fact that parents are not always aware of the siblings' feelings (Gallo & Szychliński, 2003; Guite, Lobato, Kao, & Plante, 2004; Hamama, Ronen, & Reigin, 2000; Hayes, 1997; Sharpe & Rossiter, 2002). One solution is to ask the siblings directly about their relationship with their sibling with a disability rather than rely on proxy informants (parents).

The Autism Society of America (2007) reported that siblings of children with autism report the following sources of stress: embarrassment around peers; jealousy regarding the amount of time that parents spend with the sibling with autism; frustration when they do not get a response from the sibling with autism when attempting to interact with them; being the target of aggressive behaviors; attempting to make up for the deficits of the sibling with autism; concern for parent's stress and grief; and concern over their role in future care giving. Given the importance of the sibling relationship, the developmental level of the adolescent, and the limited, consistent research on adolescent siblings, it is important to explore the relationship that the adolescent has with their sibling with autism as it relates to coping strategies used and the impact on adolescent's perception of family functioning.

The sources of stress that adolescents face have the potential to decrease the self-concept of the adolescent. Self-concept has been defined by Nurmi (2004) as the way that a person views themselves in a variety of situations. Self-concept is a cognitive appraisal that is influenced by the attitudes of peers and parents regarding such things as personal appearance, academic success, peer relationships, and athletic ability (Nurmi, 2004). Self-esteem, which is closely linked to self concept, is the way that a person evaluates themselves according to a set of standards such as the peer group or societal norms. Research has suggested that self concept of adolescents fluctuates across time and is influenced by the developmental stages of the adolescent (Nurmi, 2004). Dyson (1999) reported that siblings of children with disabilities have higher self concepts when there are psychosocial resources such as healthy family functioning, low parental stress, and social support for the sibling. Smith and Perry's (2005) study of siblings of children with autism found that a sibling support group significantly increased the self concept of the siblings. Henderson, Dakof, Schwartz, & Liddle's (2006), study of adolescents in an outpatient substance abuse program, found that poor self concept was related to perceived maladaptive family functioning. The question raised by Henderson et al. (2006) is whether there is a bidirectional influence with family functioning influencing self concept or self concept influencing how the adolescent perceives the functioning of their family. Studies that have explored issues of self concept do not report consistent results and have methodological limitations such as small sample size and no comparison group (Kaminsky & Dewey, 2002). The literature suggests that coping, family functioning, and



self-concept are interrelated, but there is a lack of direct research regarding the impact of these relationships specifically for adolescents who have a sibling with autism.

Little is known about the age and gender of the adolescents and their relationship to family functioning, self-concept, and satisfaction with the sibling relationship. It is thought that coping strategies develop during childhood and become more sophisticated as the child matures. Children's coping strategies, however, are not well understood nor are they studied from a developmental perspective (Glasberg, 2000; Hamama, Ronen, & Feigin, 2000; Lerner & Benson, 2003; Ryan, 1989). There are several reasons for the difficulty in studying the development of coping. First, there is no clearly identified theory for examining coping in children or adolescents making it difficult to effectively use the theories from a developmental perspective (Ryan, 1989). Second, the majority of the studies that examine coping and children have not focused specifically on the development of coping strategies. Third, most of this literature uses the stress and coping model and applies it to the child who has a disabled sibling without taking into account the child's developmental level (Houtzager, et al. 2004).

As children mature cognitively and emotionally they are better able to problem solve and channel their emotions so it would be logical to believe that the coping strategies that children use are dependent on age and developmental level as well. Skinner and Zimmer-Gembeck (2007) reviewed studies that examined age differences or changes in coping responses to stress. Skinner and Zimmer-Gembeck identified transition periods for coping including: late childhood to early adolescence (10-12); early and middle

adolescence (12-16); and middle and late adolescence (16-22). The most rapid development of coping occurred between the ages of 5-7 and 8-12 years. During the younger years, coping is carried out by using direct action and enlisting the help of others as needed. This trend of seeking help from others continues as children move into adolescence.

As children reach middle childhood and their cognitive development progresses, they are able to use more sophisticated techniques for coping such as distraction, delay, and problem solving, either independently or with the guidance from others. By adolescence, children's cognitive development should be in formal operations enabling adolescents to more effectively problem solve and to regulate their coping responses and anticipate future implications of decisions. Adolescents also are able to determine which adults will be best able to help them in a given situation (Skinner & Zimmer-Gembeck, 2007).

Coping is shaped in part by social relationships and contexts. Children's coping abilities develop in part by socialization and exposure to others who provide models of coping. Parents and other social supports may either be stressors themselves or may strive to buffer children from repeated stressors. Parents are also instrumental in role modeling both constructive and non constructive strategies for coping (Skinner & Zimmer-Gembeck, 2007; Zimmer-Gembeck & Locke, 2007). Ryan (1989) stated that "both adaptive and maladaptive coping strategies are learned behaviors and can be acquired, changed, or eliminated" (p. 111). Hampel and Petermann (2006) conducted a study using adolescent participants to determine if age and gender were related to interpersonal stress,

coping with interpersonal stress, and psychosocial adjustment. They found that eleven and twelve year olds used more maladaptive coping strategies resulting in an increase in externalizing problems. The authors also found that externalizing problems did not differ by gender.

Dyson (1999) explored psychosocial functioning, including self-concept, behavior problems, and social competence, in school age children who had siblings with disabilities. Dyson (1999) found that there were no significant interaction effects for participant gender on self concept. Preechawong et al. (2007) examined the relationships of family functioning, self esteem, and resourceful coping for Thai adolescents with asthma. The authors found that when gender and age were controlled as covariates, family functioning had a significantly positive impact on self esteem.

The concepts in the proposed model have been examined in the literature with inconsistent findings for children and adolescents with a variety of disabilities. In addition, the literature does not examine all concepts in the model in the same population. This study examined coping strategies, self-concept, satisfaction with the sibling relationship, age, gender, and family functioning specifically for adolescents who have siblings with autism.

## **Methods**

### **Design and Sample.**

An exploratory, correlational design was used in this study. In order to achieve the specific aims of the study, a convenience sample of 97 adolescents who are siblings of children with autism was recruited. The study was designed to have a power of at least 80% with an alpha of .05 to detect a moderate (.30) correlation as described by Polit (1996). Inclusion criteria included: age 11-20; have a sibling with autism as diagnosed on the autism spectrum disorder; have sufficient command of the English language (both reading and writing) to respond to the survey; and have access to a computer with internet access. Adolescents were excluded if they had a history of developmental or language delay.

### **Measures.**

The measures selected for this study have been used in the adolescent population. The selected measures have been designed for adolescents thus making it possible to obtain information directly from the adolescents rather than relying on parent proxy. In addition, these instruments are consistent with the concepts in the Resiliency Model of Stress, Adjustment, and Adaptation, the framework that guided this research.

### ***Background data.***

A background survey instrument was developed to collect demographic information from the adolescent. The background survey instrument also collected data regarding the age of sibling with autism, gender of sibling with autism, presence of other siblings in the family, and support group attendance (see Appendix A).

### ***Qualitative data.***

Qualitative data were collected to help inform interpretation of the quantitative data analysis. The adolescent was asked open ended questions on the survey. They were asked to describe challenges and positive experiences that they have encountered relating to their sibling with autism. For each of the challenges and positive items identified the adolescent was asked to describe the influence on themselves, their family, and friends. In addition, they were asked how they handled the challenges that were faced and how the described item made them feel about their sibling with autism. There were 85 respondents for each of the qualitative survey questions (see Appendix A).

### ***Adolescent Coping.***

The *Adolescent Coping Orientation for Problem Experiences* (A-COPE) (McCubbin, Thompson, & McCubbin, 2003) assesses coping strategies used by adolescents 12-18 years of age. The A-COPE questionnaire includes 54 questions and requires approximately 10 minutes for the adolescent to complete. The adolescent is asked “When you are faced with difficulties or feel tense how often do you...” The responses are

based on a 5 point Likert scale (1 = Never, 2 = Hardly, 3 = Sometimes, 4 = Often, and 5 = Most of the time). Twelve subscales are obtained and are labeled: ventilating feelings (expression of frustration such as yelling), seeking diversions (efforts to keep busy to escape the stress), developing self-reliance and optimism (efforts to take charge of the situation), developing social support (efforts to stay emotionally connected), solving family problems (working out issues with family members), avoiding family problems (communicating feelings to family and following family rules), seeking spiritual support (praying or going to church), investing in close friends (seeking closeness and understanding from peers), seeking professional support (getting professional advice from counselor or teacher), engaging in demanding activities (becoming involved in challenging activities to excel at something), being humorous (making light of the situation), and relaxing (reducing tension through such activities as listening to music). Cronbach's alpha ranged from .50 (seeking professional support) to .76 (investing in close friends) (Patterson & McCubbin, 1987) (see Appendix A).

Summing the scores for each item in the subscale gives a score for each of the subscales. Coping patterns that are used more frequently will have higher scores than those used less frequently. A total score for the A-COPE can be calculated by summing the participant's responses for each item. Nine items (7, 8, 19, 24, 26, 28, 42, 46, and 49) need to be reversed scored so that all items are weighted in a positive direction (Snethen, et al. 2004).

### ***Family Functioning.***

The *Family Assessment Device* (FAD) is a 60-item instrument that takes approximately 15-20 minutes to complete (Neabel et al. 2000). The FAD assesses family functioning on six dimensions: problem solving, which assesses the ability of the family to resolve problems together; communication, which examines the effectiveness of the communication in the family; roles, which examines how family tasks are assigned and if those tasks are completed; affective responsiveness, which addresses the ability of the family members to respond to situations with appropriate emotions; affective involvement, which looks at the degree of interest that is shown in other family member's lives; and behavior control, which describes the expectations for behavior. In addition, the instrument has a general functioning subscale that assesses the overall health of the family. The general functioning subscale is an independent scale that does not include items from the previously mentioned subscales (see Appendix A). Cronbach's alpha for the subscales range from .72 - .92 (Epstein, et al. 1983; Neabel et al. 2000; Tamplin & Goodyer, 2001).

Responses to items are based on a Likert scale that ranges from 1 strongly disagree to 4 strongly agree. Scores for each subscale are averaged with higher scores indicating less healthy functioning. Cut off values for healthy and unhealthy families have been established for each subscale and range from 1.9 (behavior control) to 2.3 (roles). The general functioning subscale is comprised of 12 items whose scores range from 1 (healthy) to 4 (unhealthy). The general functioning scores are averaged with a cut off

score of 2.0 distinguishing between well functioning and poorly functioning families. These cut-off values have acceptable sensitivity, specificity, and positive predictive value (Neabel et al., 2000). There is clear empirical evidence that this instrument is reliable and valid and operationalizes the concept of family functioning. The feasibility and utility of the FAD is also evident. The reading level is at 6<sup>th</sup> grade which is appropriate for not only adults but also for adolescents (Redman, 2001).

### *Children's Self Concept.*

The *Piers-Harris Children's Self Concept Scale 2* (Piers & Harris, 1984) is a 60 item self report yes/no questionnaire that examines children's self appraisal in such domains as behavior, intellectual and school status, physical appearance and attributes, anxiety, popularity, and happiness and satisfaction, as well as a total score for the scale which is used in the analysis. A positive response receives a score of 1 and a negative response receives a score of 0. A total raw score as well as a percentile score can be calculated by summing the responses. Scales for each subscale can also be obtained by summing the responses. The total score on the Piers-Harris Children's Self Concept scale has the most research support. The raw scores for the total score range from 0-60. The normalized raw scores are converted to *T-scores* so percentile ranks are consistent across all of the scales. The total score is broken into high ( $\geq 60T$ ), average ( $40T-59T$ ), and low ( $\leq 39T$ ) range (Piers & Herzberg, 2007). A higher score indicates a higher self concept (Dyson, 1999; Smith & Perry, 2005). The Piers-Harris Children's Self Concept Scale 2 can be used



reliably in children as young as seven years old and has been studied in siblings of children with autism and other developmental disabilities (Dyson, 1999; Mates, 1990; Smith & Perry, 2005) with good reliability ( $\alpha = .78-.93$ ). Closely linked to reliability is consistency. Test-retest reliabilities range from .71-.77 (Dyson, 1999). The internal consistency combined with good test-retest reliability makes this a psychometrically sound measure. This measure takes approximately 10 minutes to complete (see Appendix A).

***Satisfaction with the Sibling Relationship.***

The *Satisfaction with the Sibling Relationship Scale* (McHale & Gamble, 1989) was used to examine the adolescent's satisfaction with their sibling relationship in six domains: overall happiness having their sibling as a brother or sister, time spent with siblings, time spent in caretaking, how the siblings get along, parent's relative treatment, and parent's relative attention. Rivers and Stoneman (2003) modified the scale to use a 5 point Likert response and siblings were asked to report on behavior in the past three months. Coefficient alpha was .80 in the reviewed study. Scores for the *Satisfaction with the Sibling Relationship Scale* are summed across dimensions with higher scores indicating more satisfaction with the sibling relationship. This scale should take the adolescent approximately 5 minutes to complete (see Appendix A).

## **Procedure**

Approval for use of human subjects was obtained from the Institutional Review Board of the University of Michigan (IRBHealth) and Western Michigan University. Adolescents who have siblings with autism were recruited via the Interactive Autism Network (IAN) community web site ([www.ianproject.org](http://www.ianproject.org)). Researchers, with proper permission from the Human Subjects Internal Review Board and written verification of status from the school of study, are able to post research opportunities for families of children with autism. Cover letter emails were sent by the research coordinator for IAN to parents of children with autism enrolled in IAN who had adolescents who met the eligibility criteria (see Appendix B). Initially, 713 emails regarding the research study were sent. Seventy-two adolescents completed the survey during a two month period. When responses slowed, the IAN research coordinator was contacted and 300 more emails regarding the research were sent resulting in ten more completed surveys. As a sample size of 92 was needed to have sufficient power, the survey was sent to 120 people resulting in six more completed surveys. A reminder email was sent to the final 120 people resulting in nine more completed surveys giving a total of 97 participants. Parents of adolescents 11-17 gave consent (see Appendix C) for their adolescent to participate in the study and the adolescent gave their assent for participation (see Appendix C). Adolescents who were over the age of 18 were able to give their own consent for participation in the study (see Appendix C). In the informed consent, parents were

requested to allow their adolescent privacy while completing the questionnaires so that confidentiality for the adolescent can be maintained.

### **Data Collection Procedures.**

Data collection was completed through the use of Survey Monkey. The instruments were loaded into Survey Monkey for ease of answering the questions. The IAN information for parents included a description of the study, the purpose of the study, eligibility criteria, risks, benefits, and rights of being a study participant. Once the parent had an opportunity to review the IAN letter and description of the study, they could give their consent and were connected to the survey. The adolescents also read an informed assent form prior to participating in the study. They, too, received a description of the study, purpose of the study, eligibility criteria, risks, benefits, and rights of being a study participant. Submission of the measures implied consent/assent from the adolescent. The subjects completed the measures on a computer in a location that was comfortable for them as well as at a time that was convenient for them. Background and qualitative information were collected to help inform the quantitative portion of the data. Completion of the measures took approximately 30-45 minutes. Subjects could take a break by pausing the survey at any time and resuming the survey at a later time. A \$10 Amazon gift card was given as an incentive for completion of the survey. The participants needed to provide their email address and a colleague of the researcher had

access to only the email addresses to send out the gift card. The colleague did not have access to the data nor did the researcher examine the email addresses of the participants.

Survey Monkey guarantees anonymity and the data were stored on a password protected computer thus ensuring confidentiality for the adolescent completing the survey. There was no way for the researcher to link the parent or the adolescent's identity to the adolescent's responses. Following collection and analysis of the data, the data were stored on a computer disc in a locked drawer in the principal investigator's office.

### **Data Analysis**

The data obtained from Survey Monkey was downloaded into SPSS 15.0 for data analysis. Prior to analyzing the data, the demographic data were examined. The reliabilities of the instruments were examined. Path analysis using multiple regression was used to determine the fit of the proposed model.

### **Sample Description.**

The sample consisted of 97 adolescents who have a sibling with autism and whose parent(s) are members of the Interactive Autism Network (IAN). The adolescents ranged in age from 11-19 years, were primarily Caucasian (n=85, 87.6%), and 82.5% (n=80) had a brother with autism. These data supports the literature that more males than females are affected with autism (ASA, 2009). The sibling with autism ranged in age from 3-18 years. Gender of the adolescent sibling was not collected on the initial survey making it necessary for a colleague to email the participants to see what their gender was

in addition to updating the survey with the gender information (n=53). More than half of the adolescent siblings had other siblings in addition to the sibling with autism. Looking at the family constellation revealed that most respondents lived with their mother, father, and sibling with autism (see Appendix E).

## **Results**

Path analysis using multiple regression was used to determine the predictive ability of the model. Each of the instruments general functioning or total scale was entered into the regression analysis as there was no literature to support which variable had the most influence on family functioning (the dependent variable). As the gender of the participants was not collected initially resulting in 53 of 97 participants having gender recorded, the regression analysis was run with replacing the missing value with the mean, using listwise and pairwise deletion. After reviewing the results, the decision was made to use pairwise deletion as this method provided the best fit for the model. The collinearity statistics were examined and there was no collinearity identified in the model. The reliability for each of the total scales for the instruments were .93 (Piers-Harris Children's Self Concept Scale), .90 (FAD) .86 (Satisfaction with Sibling Relationship Scale), and .85 (A-COPE). All reliabilities are in the acceptable range as they are  $> .80$ .

Using the perception of family functioning as the dependent variable, the coping strategies that the adolescents use, how they perceive themselves through their self-concept, how happy they are with their sibling relationship as well as their age and

gender explain 44.2% of the variance ( $R^2=.442$ ). The multiple regression analysis revealed significant negative relationships for coping, self-concept, and satisfaction with sibling relationships with family functioning. The other path relationships were not significant (see Appendix D).

## **Discussion**

The model included coping strategies, adolescent self concept, satisfaction with the sibling relationship, age, and gender explained 44% of the variance in family functioning. The model demonstrated that there were three significant negative relationships with family functioning: the coping strategies used, the adolescent's self concept, and the overall happiness with their sibling relationship. The coping strategies that adolescents use were thought to impact their perception of how their family functions. When an adolescent is choosing not to spend time with the family, either because they are in their room listening to music, spending time at a friend's house, or finding other activities to be involved in as a result of feeling left out if because their parents are spending time with their sibling with autism, their perception of family functioning will be altered. While there are few studies that examine coping strategies and family functioning in the same adolescent group, one study did examine coping strategies and family functioning from the caregiver of a child with autism's perspective. Higgins et al. (2005) used multiple regression to examine whether coping strategies, along with other variables, influenced family functioning, (operationalized as family

cohesion and adaptability). Their results showed no significant relationships between coping strategies and family functioning. The fact that caregivers and adolescents demonstrated different results could be related to developmental aspects. Caregivers do not have the option of spending time away from home with friends as often as an adolescent would nor would they be as likely to feel left out of family activities. It is important for parents of children with autism to be aware of the time that their adolescent is spending either away from home or isolated in their room. Making time to spend with the adolescent in one on one time is an important intervention for parents. One adolescent remarked “My mom doesn’t have a lot of time between work, doctor’s appointment, and therapy and just taking care of my brother, a lot of the times to just spend time with me. She really tries to have time with just me.” Another adolescent commented that “Sometimes I can’t get help with stuff until he goes to bed or finds something to do.” These adolescents understand that their siblings require much time yet their parents make an effort to spend time with them even though it may not be at the exact time that they want to spend time with their parent or get assistance with something. Another theme that was identified was that families who have children with autism either do not or rarely go places together as a family. Adolescents reported that they “couldn’t go anywhere as a family” and “some things we can’t do without someone watching my brother, which isn’t always possible.” Children with autism are a part of the family. As one adolescent stated “I was so little when he was diagnosed, I wouldn’t know the differences. I’ve grown up with the family with autism in their lives.” Trying to make family time is difficult with

the busy schedules that most families keep. In a family where there is a child with autism, trying to find family time is even more difficult. The autistic child is part of the family yet many times the behaviors that the child displays are the very things that keep families from doing things together. Finding respite for the family of a child with autism is not always easy. If a family is fortunate enough to have respite, they could use that time to spend with the other siblings in the family so that those children feel less isolated which could change the perception of how their family functions. The adolescents identified that many times there was yelling in the house and at times this yelling was directed at them. This made them withdraw or spend more time with a friend's family to avoid the yelling and ensuing stress. Families need to work together to have healthy family functioning. This means that family members must feel comfortable sharing their feelings with each other, knowing that their opinions will be listened to and respected. Other family members need to listen with an open mind and work collaboratively to find a solution that will improve the perception of family functioning.

The way that adolescents feel about themselves permeates many facets of their life including how they perceive their family. Adolescence is a time to fit in with peers, transition away from home, and become more independent, making the family relationship second to peers and their own interests. For a family with a child with autism, the adolescents may be forced to spend more time at home to care for their sibling with autism or be expected to participate in more household tasks (Cox et al. 2003). The model shows that there is a significant negative relationship between self



concept and the perception of family functioning. The negative relationship between self concept and family functioning is contrary to what (Henderson et al. (2006) found in their study of 224 adolescents who were in a substance abuse treatment program. Henderson et al. (2006) concluded that decreased self concept is related to more maladaptive views of family functioning. Dyson (1999), who examined 71 school age children who had siblings with and without disabilities, reported the same directionality but looked at it from a more positive perspective in that the participants self concept was positively related to positive family function. The mean raw score for the total scale for this group of adolescents was 41.88 (range 14-59) indicating that the adolescents in this sample had self concepts in the average range. Piers and Herzberg (2007) report that scores in the average range represent a balanced self assessment of self concept with scores that are consistent with those in the standardization sample. The FAD scores were just above the cut-off scores for healthy family functioning in problem solving, communication, roles, affective involvement, and general family functioning (see Appendix E) indicating that adolescents perceived that their family did not have healthy family functioning. Sixty percent of the adolescents surveyed possessed an average self concept. Thus, it is not surprising that their family functioning cut-off scores were just above those for healthy family functioning: no scores were either very high or very low in relation to the cut-off point but clustered around the threshold scores. Self concept and the coping strategies that these adolescents used were unrelated; similarly, neither age nor gender influenced self-concept.

The sibling relationship is unique in that it is long lasting, provides a sense of companionship, and teaches children how to socialize with others. For many siblings of children with autism, the sense of companionship and learning to socialize is missing. That the relationship is long lasting means that siblings of children with autism may have to take on care taking duties for their sibling if their aging parents are unable to provide care while trying to maintain a family or life of their own. Adolescents were asked about their overall happiness with their brother or sister with autism and 58 (49%) responded that they were happy with their sibling with autism. The model shows a significant negative relationship between the overall happiness of the sibling relationship and perception of family functioning. While the FAD cut-off scores for healthy family functioning were exceeded as previously mentioned, adolescents were overall happy with their relationship with their sibling with autism ( $M = 6.55$ ,  $SD = 2.53$ ). This was also supported in the qualitative results. Adolescents reported that there were positive things about growing up with a sibling with autism which contributed to the overall happiness they had for their sibling. Many adolescents expressed that their sibling was loving, with one adolescent stating “he has such a good heart and is always there to give a hug when you need one.” Another adolescent reported “I love my brother. I would do ANYTHING for him. When I talk about him, there is so much joy that builds up in me that I usually start to tear up.” While many express happiness with their sibling relationship, there are some that were mad, upset, frustrated, and saddened by the problems that their sibling with autism has caused. The vast majority of adolescents who participated in the

qualitative analysis (n=85) had positive things to say about their sibling relationship yet their FAD cut scores were in the unhealthy family functioning range lending credence to the statistically significant negative relationship between the overall happiness of the sibling relationship and their perception of family functioning. Overall happiness with the sibling relationship was unrelated to age, gender, and coping strategies used by the adolescent.

There are several limitations to this study. First, the gender information must be evaluated with caution. Gender was not initially collected necessitating, with IRB approval, contacting the adolescents for which email addresses were present to see if they would provide their gender and adding gender to the background information form on Survey Monkey. Gender was obtained for approximately 50% of the sample. A power analysis was computed to see if gender was underpowered and the power was above .80 which was the original acceptable power that was desired. Another limitation is that while many studies examine coping strategies, family functioning, self concept, and sibling relationships few studies use the same instruments to measure each concept and even fewer use all the same instruments together making it difficult to generalize results across groups. A final limitation is the use of a convenience sample recruited from the IAN. Since the literature doesn't state what percentages of children with autism have adolescent siblings, using the IAN enabled the researcher to have enough adolescents to have an adequately powered study. It is not known if parents who participate in the IAN and who allowed their adolescent to complete the survey are different in any way from

other families who have children with autism or from those who did not allow their adolescent to complete the survey.

As this study is a beginning step in exploring relationships among coping strategies, self concept, satisfaction with the sibling relationship and family functioning, future research will examine these concepts more closely to see if self concept or happiness with the sibling relationship mediate or moderate the choice of coping strategies that adolescents use when there is a sibling with autism. Examining the subscales for the Piers Harris Children's Self Concept Scale and Satisfaction with the Sibling Relationship Scale may lead to interventions that will not only make the adolescent feel better about themselves but also may help them to identify problem areas in the sibling relationship that can be worked on with parent support.

## **Conclusion**

This study contributes to the understanding of the complexities that adolescents who have siblings with autism encounter. There were three significant, negative relationships on perception of family functioning-coping, self concept, and satisfaction with the sibling relationship. Neither the adolescent's self concept nor how happy the adolescent is with the sibling relationship demonstrated a significant relationship with the coping strategies that were used. Age and gender did not exert any significant relationship on any components of the model. Future research will include examining the

concepts in the model to see if there are mediating or moderating effects that influence the self concept of the adolescent and the choice of coping strategies that are used.

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## **Discussion**

This innovative research examines experiences of adolescents who have siblings with autism. Further, study recruitment and data collection were conducted via the web. The prevalence of autism is increasing. As more families are challenged with caring for and living with children with autism, parents as well as siblings are going to be affected. It is important to understand how autism affects all family members. There are studies that examine coping and family functioning from the parent's perspective but few studies examine these concepts from a sibling's perspective (Glasberg, 2000; Hamama et al. 2000; Lerner & Benson, 2003; Ryan, 1989). It is necessary to study the sibling's perspective by asking the sibling as parents do not always know and understand how the siblings are thinking and feeling (Gallo et al. 1991, Gallo & Szychlinski, 2003; Guite, Lobato, Kao, & Plante, 2004; Hamama et al. 2000; Hayes, 1997; Sharpe & Rossiter, 2002). The current descriptive/correlational study asked adolescents 11-20 years of age to complete a web based survey about their experiences as a sibling of a child with autism, without input from parents. Qualitative as well as quantitative data were collected. The qualitative data were collected to help inform the quantitative results. As parents had access to both the quantitative and qualitative questions, it was hoped that discussion would be generated between parents and children that will tackle some of the tough issues that these families face.

Adolescents were recruited from the Interactive Autism Network (IAN) which is a website for families who have children with autism. The IAN research coordinator emailed families who had adolescents that would be eligible for the study to solicit their participation. Adolescents who had parent consent and gave their assent were able to access the link to the Survey Monkey website. Having an online survey and using the IAN was beneficial in that it allowed access to families in different geographical areas. As the literature doesn't estimate the number of adolescents who have siblings with autism, the web based survey and recruitment through the IAN enabled the sample size to be easily obtained. Using computerized data collection has several advantages over pencil and paper questionnaires or face-to-face interviews including: avoidance of data entry errors; conditional branching embedded in the program; fewer incomplete responses; sense of more confidentiality as there is no paper trail; and greater reporting of sensitive behaviors minimizing socially desirable responses (Mangunkusumo, Moorman, Van Den Berg-de Ruyter, Van Der Lei, De Koning, & Raat, 2005; Vereecken & Maes, 2006; Webb, Zimet, Fortenberry, & Blythe, 1999). Research suggests that adolescents are enthusiastic about using computerized questionnaires and rate the computerized interface highly (Mangunkusumo, et al; Vereecken & Maes; Webb et al).

The coping strategies that adolescents use were measured using the A-COPE instrument. While the reliabilities for the subscales were less than desired (.31-.81), the reliability for the total scale was .85. A-COPE is one of the few tools that measures coping from the adolescent perspective and was developed out of the Resiliency Model

of Stress, Adjustment, and Adaptation, the framework which guided this research study. The coping strategy subscale that adolescents in this study used most often was that of seeking diversions which included items such as watching television, playing video games, sleeping, reading, and being involved in a hobby. The least frequently used subscale was seeking professional support which included items such as talking with a teacher or counselor and getting professional counseling. The qualitative data, which included a question about how the adolescents handled problems with their sibling with autism, reinforced that adolescents do watch television, get involved in a hobby or sleep. While there was not a specific question that related to talking with a counselor or teacher in either the qualitative information or the background information, there was a question regarding participation in a support group. Seventy five percent of the adolescents in the study had never attended a support group and sixty five percent did not know if there was a support group in their area. The Interactive Autism Network (IAN) is not intended for use in children younger than 18, so while parents may find support and tips for dealing not only with their child with autism but sibling issues as well, this site does not provide support for adolescents. No adolescents mentioned participating in online support or chat room conversations. Having a secure portion of the IAN site for adolescents to share their feelings, suggestions for dealing with their sibling with autism, and help them connect with others who understand what they are experiencing may decrease the isolation that these adolescents feel. As one adolescent with a sibling with autism stated “you don’t know what it is like until you live with autism.” Creating a space where conversations

could take place could serve to decrease some of the isolation that these adolescents feel. Another adolescent indicated in their qualitative response that they “appreciate being able to talk with others about autism.” This statement validates that talking with someone who understands or who is trying to understand what living with a sibling with autism is like is not only a unique experience but appreciated as well.

There were differences between males and females on the coping strategies that were used. Three of the A-COPE subscales, developing social support, investing in close friends, and relaxing, showed significant differences in the use of these specific coping strategies used between males and females. For all three subscales, females used each of these coping strategies more frequently than males. This is consistent with the feminist developmental perspective which states that for females caring and relationships are more of a developmental priority than identity acquisition (Gilligan, 1982).

It was hypothesized that older adolescents would use more coping strategies than younger adolescents. This hypothesis was not supported: younger adolescents used more coping strategies than the older adolescents. This may be due in part to the fact that children with chronically ill siblings take on more adult roles at an earlier age (Cox et al. 2003; Morgan, 1988). The youngest adolescents used more problem solving approaches, which was contrary to what was expected. This finding could be due in part to the items in the solving problem subscale, which includes some social support items such as talking with mother, father, or siblings. Younger adolescents are more likely to engage in these discussions whereas older adolescents spend more time on average with peers. This

finding is consistent with that of Skinner and Zimmer-Gembeck (2007) who also found that when problem solving approaches were decreased in the older adolescents, the items in the scale included social support seeking behaviors such as talking with parents or siblings.

While fewer coping strategies were used by the older adolescent group, they did use more sophisticated coping strategies such as looking at problems optimistically. Older adolescents are cognitively more mature and future directed. The optimism could be rooted in the fact that older adolescents have a broader perspective and are planning for college or a life out of the home without their sibling with autism. Older adolescents also used relaxation, investing in friends, humor, and seeking diversion more frequently than the younger adolescent age groups which is consistent with their ability to take a ride in the car, go to a friend's house, drive to the movies, and have a perspective on things that they can make light of a situation. Younger adolescents developed more social support than those in middle adolescence. It would seem that developing social support would be reflected in items such as spending time with friends and family. The social support subscale includes these items but also includes crying, saying nice things to people, and apologizing. These emotion focused items are less likely to be used by older adolescents due to the fact that as their cognitive development increases, they are better able to use cognitive strategies to deal with an issue before using emotion focused strategies (Skinner & Zimmer-Gembeck, 2007). Future research should examine the development of coping strategies when there is a child with chronic illness in the family

to confirm that coping strategies mature earlier when there is a child with a chronic illness such as autism.

Family functioning is an important concept to consider for all families and is especially important for families of children with autism. There is limited literature that examines how families that have children with autism function. The extant data on family functioning and autism have been collected from the parent perspective. In contrast, the current study was novel in that the information was gathered directly from the siblings. The FAD has set cut points on the instrument subscales that define healthy family functioning. The results of the FAD demonstrated that adolescents who have siblings with autism perceive their family functioning in the unhealthy range on five of the seven subscales: affective involvement, problem solving, communication, roles, and general functioning. Two of the scales, behavioral control and affective responsiveness, were in the healthy family functioning range. These results were not surprising as parents report that they have little time to spend with siblings and one parent reported that the well sibling will never be a priority (DeGrace, 2004). Roelofse and Middleton (1985) used the Family Functioning in Adolescence Questionnaire (FFAQ), which measures family functioning focusing on the developmental tasks of the adolescent. They found that the healthy adolescents who participated in the development of this questionnaire viewed their families positively overall. The sample in Roelofse and Middleton's study did not mention the health of the adolescent's sibling. While the two instruments don't measure all the same items, nor does the FFAQ have a cut score for healthy family functioning,



the results do lend credence to the fact that adolescents are able to view their family functioning in a positive way. As the scores for the adolescents in the current sample clustered close to the cut scores, it is reasonable to ask if all adolescents, regardless of the health of their siblings, perceived their family functioning in an unhealthy manner.

There were no differences in perceptions of family functioning by age or gender for adolescents in this study. It was proposed that there might be differences across age groups as older adolescents, who have more mature cognitive development, would be able to examine their family functioning in a more objective way. One factor to consider is that adolescents, regardless of their age, have more mature cognitive development due to having a sibling with autism with the responsibilities that are inherent in helping provide care for that sibling. It can be conjectured that females, who typically participate in more caregiving activities than males (Dyson, 1999; Gupta & Singhal; Leonard, 1991; Mascha & Boucher, 2006; McHale & Gamble, 1987; Rodrigue et al. 1993) would perceive that their family is functioning in a less healthy way. Although the results of this study did not support this conjecture, this finding may be related to missing data on gender. The results related to gender data should be interpreted with caution.

The proposed model of family functioning, coping strategies, adolescent self-concept, satisfaction with the sibling relationship, age, and gender explained 44% of the variance in family functioning. The model demonstrated that there were three significant negative relationships for family functioning: the coping strategies used, the adolescent's self-concept, and the overall satisfaction with their sibling relationship. Thus, the findings

indicate that the more coping strategies, the more positive self-concept, and the greater the overall happiness with their sibling relationship, the less positive the family functioning. It was proposed that the relationships would be significant, but in a positive direction. Two studies that examined the relationship between family functioning and coping found conflicting results. Higgins, Bailey, and Pearce (2005) found that the relationship between coping style and family adjustment was not significant while Preechawong et al. (2007) found that family functioning influenced resourceful coping in Thai adolescents with asthma. Both of the aforementioned studies were conducted with parents and not adolescents which could explain, in part, the differing results in the current study. As the sample of adolescents in the current study had an average age of 14 years, the coping strategies that they use should be different from that of adults. The adolescents in the sample rarely used prescription or non prescription medications, drank alcohol, or smoked as a coping strategy but rather sought diversion in music, watching television, and reading. The result that the adolescents in this sample used coping strategies that were consistent with other adolescents their age, but there was a significant negative relationship with perceived family functioning needs further investigation. Future studies need to address whether adolescents who have siblings without autism or other chronic diseases use the same coping strategies as the adolescents in the sample for the current study and if the family functioning measures have cut scores about the level for healthy family functioning. The model results inform the development of interventions. As the adolescents use coping strategies that are consistent with their

developmental age, have a balanced self-concept, and are satisfied with the relationship with their sibling with autism, interventions should be directed at the family system. Improving communication among family members should result in the perception of healthy family functioning as communication is at the heart of the five subscales that were found to be in the unhealthy family functioning range. Encouraging parents to communicate with their children regarding the child with autism and providing rationale for some of the family decisions would improve the sibling's understanding of what is occurring in the family not only about future plans for the child with autism but about roles that each family member has in the family. Parents and adolescents need to be encouraged to listen to each other and respect the feelings of other family members. Parents need to be encouraged to be available to the adolescent siblings and show interest in their activities. It is important to build on the strengths that the family has in the way that they express emotions and have clear expectations for behavior.

The sibling relationship is dynamic and provides a place for siblings to learn to interact with each other in a safe environment. For adolescents who have a sibling with autism, this relationship does not always exist as many children with autism are not able to communicate with their sibling. If there is one child in the family who is favored over another or if there are sibling relationships that are in constant conflict, family functioning and the sibling's adjustment and psychological well-being are at stake (Richmond & Stocker, 2006). Many times adolescents in this study would express mixed emotions of happiness, sadness, embarrassment, and joy all in one sentence when talking

about having a sibling with autism. The mixed emotions reflect the complexity of not only the sibling and family relationships but also of autism itself. It was interesting to note that 49% of the sample reported being happy with the relationship with their sibling with autism. Again, further research is necessary to ascertain whether adolescents who do not have siblings with autism or chronic diseases have similar results as the adolescents in this sample or if there are differences across adolescents with a sibling with a chronic disease other than autism and those with a sibling with autism. As adolescents who have siblings with autism express happiness with their sibling relationship, there are other factors that are potentially influencing the perception of family functioning for adolescents in this study.

The self-concept of the adolescent was another construct that was included in the model. Dyson (1999) found that self-concept was related to positive family functioning. Henderson, Dakof, Schwartz, & Liddle (2006), while examining adolescents in an outpatient substance abuse program, found that an adolescent's poor self-concept was related to perceived maladaptive family functioning. The mean raw score for the total scale for this group of adolescents in this study was 41.88 (range 14-59) indicating that the adolescents in this sample had self-concepts in the average range. Piers and Herzberg (2007) reported that scores in the average range represent a balanced self assessment of self-concept with scores that are consistent with those in the standardization sample. This may indicate that having a sibling with autism does not contribute to a lower self esteem than adolescents who do not have a sibling with autism.

There are several strengths to this study. The online survey facilitated by the IAN enabled adolescents from various parts of the country to participate. The online survey format was appropriate for adolescents as they are familiar with computers and social networking sites as well as feeling that their answers are more likely to be anonymous than if they answered face-to-face questions or used a pencil and paper format. While there is still much that is to be learned, this study provides a beginning understanding, from the sibling perspective, what it is like to live with a sibling with autism.

### **Limitations**

There are limitations to this study. This was a convenience sample of adolescents whose parents are members of the IAN. It is not known if parents who participate in an online group such as IAN are different than parents who do not. Parents who do not participate in IAN may be unaware that such a tool is available to them and their family for support and research opportunities for their child with autism. The demographic information was collected at the end of the survey. This did not allow the researcher to obtain information on adolescents that did not complete the entire survey for comparison on similarities and differences for adolescents who did complete all the information.

Another limitation was that gender was not initially collected on the demographic information necessitating that participants who provided email addresses to receive the incentive for completing the survey be contacted by the colleague of the researcher who sent out the incentives inquiring about their gender. The collected information as well as

those that completed the survey after gender was added to the background information resulted in approximately 50% of the subjects have gender information recorded. Any gender analysis needs to be interpreted with caution in light of this information.

Another limitation was the numbers of participants in each of the age categories for adolescence. As there were few data on how many adolescents had siblings with autism, the age categories for early, middle, and late adolescence were not specifically recruited resulting in two times as many adolescents in the middle adolescent group than either the early or late adolescent groups. Finally, there was no control group to compare if adolescents with siblings with autism are different in the coping strategies that they use, their self-concept, how satisfied they are with their sibling relationships, and how they perceive their family functions from other adolescents with siblings without chronic illnesses or with other chronic illnesses.

### **Future Research**

There is much that remains unknown regarding the adolescent experience of having a sibling with autism. Future research needs to examine more closely the development of coping strategies and explore if children and adolescents who have siblings with chronic illnesses develop more varied coping strategies at an earlier age than do children and adolescents who do not have siblings with chronic illnesses. Having an equal number of subjects in each adolescent grouping would be a beginning step to exploring this phenomenon. In addition, closer examination of the A-COPE subscales

with a larger sample would allow factor analysis to take place to explore if the items in the subscales may be better placed in different subscales to increase the reliability of the subscales.

Future research also needs to examine the perception of family functioning both from the adolescent and parent perspective to see how members of the same family perceive that their family functions when there is a child with autism in the house. Addition of control groups of parents and children who have children with no chronic illnesses or a different chronic illness in the family would allow the researcher to see if a chronic illness such as autism does influence how an adolescent perceives their family functioning or are scores on the family functioning scale consistent for adolescents regardless of if their sibling has a chronic illness.

The model that was tested explained 44% of the variance on factors that influence family functioning leaving 56% of the variance unexplained. Further research is needed to explore other factors besides coping strategies, self-concept, satisfaction with the sibling relationship, age, and gender that influence the perception of how a family with a child with autism functions. Delving more deeply into the relationships of self-concept and the sibling relationship as well as further exploration of the qualitative data may lead to additional concepts that should be included in the model or to see if there are factors that mediate or moderate the concepts in the model.

### **Implications for Practice**

The complexity of autism and the influence on other family members is so varied that a one approach fits all is not going to be successful when designing interventions for siblings and families living with autism. Nurses are in a prime position to work with these adolescents and families to improve the perception of family functioning. One way that nurses can intervene is to have a meeting with all family members, including siblings, to see what challenges they are facing and what aspects are going well. Building on the strengths of the family is one step toward lessening the challenges. Opening the lines of communication among family members can be a starting point. Family members can function more effectively when they feel comfortable sharing their feelings with each other, knowing that their opinions will be listened to and respected. Other family members need to listen with an open mind and work collaboratively to find a solution that will strengthen family relationships and make each family member feel that their opinion is valued.

Asking specific questions about the challenges that the adolescent is facing with their sibling with autism and how they are handling that challenge would begin a dialogue that would not only shed light on the coping strategies that the adolescent is using but would also be a starting point for interventions to help adolescents develop coping strategies that may work more effectively. In addition, resources for either face-to-face or online support groups could be provided. This resource may be especially helpful for adolescents who identify that they do not interact with friends due to their



sibling with autism or for those who feel that they are not getting the attention that their sibling with autism is receiving. Sharing with others and realizing that others are having the same feelings may not only help with the isolation some of these adolescents feel but may also connect the adolescent to new friends, either through face-to-face contact or through social networking sites, who can understand what they are experiencing.

### **Conclusions**

While much was learned in this beginning study, there is still more that needs to be studied in order to have a better understanding of the experience of adolescents who have siblings with autism. Adolescents use a variety of coping strategies when they have a sibling with autism with seeking diversion being the most common strategy that was used by the adolescents in this sample. It was also found that for this sample the younger adolescents used a greater variety of coping strategies than older adolescents. This was an unexpected finding but could be in part related to children who have siblings with chronic illnesses maturing quickly due to the responsibilities that they are required to undertake. Adolescents in this study also perceived that their families functioned in the unhealthy range for five of the seven subscales of the FAD. There was no difference in family functioning when examining age or gender. The model that was tested using family functioning as the dependent variable demonstrated that there were three significant, negative relationships on perception of family functioning-coping, self-concept, and

satisfaction with the sibling relationship and explained 44% of the variance. None of the other paths in the model were significant.

Nurses can work with families to open lines of communication so that all family members can have a voice and share in a nonthreatening environment what they are thinking and feeling thereby improving family functioning. Nurses should assess the coping strategies adolescents are using and either reinforce current strategies or recommend more appropriate strategies. Nurses can also provide information for adolescents on support groups for siblings of children with autism in order to provide a venue for sharing their experiences with other adolescents who understand what they are going through. If there is not a support group in the area, on-line support group resources could be explored or perhaps a support group could be started with other adolescents who live in the same area.

There are many areas that still need to be explored for adolescents who have siblings with autism. The development of coping strategies is still unclear. It is necessary to examine if the coping strategies are different for adolescents who have siblings with chronic illness versus those that have typically developing siblings. Further research is also needed to explore if adolescents who have siblings with autism perceive their family functioning any differently than adolescents who have typically developing siblings. Obtaining data from parents as well as adolescents regarding how they perceive their family functioning can provide insight into differences and also serve as a source of intervention to improve the perception of family functioning. Finally, exploring other

concepts that help to mediate, moderate or further explain the variance relating to family functioning will increase the understanding of the experience of having a sibling with autism and can lead to further interventions that strengthen families.

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## Appendices



## Appendix A

### Background Information

What is your age?

What is your gender?

What is your race/ethnicity?

Who lives in your house with you?

List their relationship to you and how long they have lived with you

Who has autism-a brother or a sister?

How old is your brother or sister with autism?

Do you have any other brothers or sisters?

If no, go to next question

If yes, list their ages, include the brother or sister with autism

How does your brother or sister with autism talk with you? For example do they use words or a picture board or something else (If you choose something else please list what that is)

Are you happy with the way that your brother or sister with autism talks with you? Please explain

List any care taking activities that you do for your brother or sister with autism and how much time you spend doing these on a typical day? Categories for each < 1hour, 2-3 hours, 4-5 hours, >6 hours

Babysitting after school

Babysitting at night

Babysitting on the weekend

Play with brother or sister at your parent's request

Feed your brother or sister

Dress your brother or sister

Bathe your brother or sister

List any household tasks that you do above what your friends do, ie laundry, grocery shopping, getting family meals, etc. and how much time you spend in these activities in a typical day. Categories <1hour, 2-3 hours, 4-5 hours, >6 hours

How satisfied are you with the time you have for your own activities?

Is there is a support group for adolescents who have a brother or sister with autism in your area?

Have you ever attended a support group for children or adolescents who have a brother or sister with autism?

Do you currently attend a support group for adolescents who have a brother or sister with autism?

How often do you go to the support group?

How does it help you?

### Qualitative Questions

Tell me about any problems that you have had growing up with a brother or sister with autism.

How did you handle the problem?

How did it make you feel?

How did it make you feel about your brother or sister with autism?

How did it affect your family?

How did it affect your friends?

Tell me about positive experiences that you have had growing up with a brother or sister with autism.

How did it make you feel?

How did it make you feel about your brother or sister with autism?

How did it affect your family?

How did it affect your friends?

Is there anything else that you would like to tell me?

## Adolescent Coping Orientation for Problem Experiences Questionnaire

Joan M. Patterson      Hamilton I. McCubbin

Purpose: A-Cope is designed to record the behaviors adolescents find helpful to them in managing problems or difficult situations which happen to them or members of their families.

*Coping is defined as individual or group behavior used to manage the hardships and relieve the discomfort associated with life changes or difficult life events.*

### Directions

- Read each of the statements below which describes a behavior for coping with problems.
  - Decide how often you do each of the described behaviors when you face difficulties or feel tense. Even though you may do some of these things just for fun, please indicate only how often you do each behavior as a way to cope with a problem
  - You will choose from one of the following responses for each statement:
    - 1-Never
    - 2-Hardly Ever
    - 3-Sometimes
    - 4-Often
    - 5-Most of the Time
  - Please be sure and circle a response for each statement
- (These were on Survey Monkey with the responses next to the statements)

When you face difficulties or feel tense, how often do you:

1. Go along with parents' requests and rules
2. Read
3. Try to be funny and make light of it all
4. Apologize to people
5. Listen to music-stereo, radio, etc.
6. Talk to a teacher or counselor at school about what bothers you
7. Eat food

8. Try to stay away from home as much as possible
9. Use drugs prescribed by a doctor
10. Get more involved in activities in school
11. Go shopping; buy things you like
12. Try to reason with parents and talk things out; compromise
13. Try to improve yourself (get body in shape, get better grades, etc.)
14. Cry
15. Try to think of the good things in your life
16. Be with a boyfriend or girlfriend
17. Ride around in the car
18. Say nice things to others
19. Get angry and yell at people
20. Joke and keep a sense of humor
21. Talk to a minister/priest/rabbi
22. Let off steam by complaining to family members
23. Go to church
24. Use drugs (not prescribed by a doctor)
25. Organize your life and what you have to do
26. Swear
27. Work hard on schoolwork or other school projects
28. Blame others for what's going wrong
29. Be close with someone you care about
30. Try to help other people solve their problems
31. Talk to your mother about what bothers you
32. Try, on your own, to figure out how to deal with your problems or tension
33. Work on a hobby you have (sewing, model building, etc.)
34. Get professional counseling (not from a school teacher or school counselor)
35. Try to keep up friendships or make new friends
36. Tell yourself the problem is not important
37. Go to a movie
38. Daydream about how you would like things to be
39. Talk to a brother or sister about how you feel
40. Get a job or work harder at one
41. Do things with your family
42. Smoke
43. Watch T.V.

44. Pray
45. Try to see the good things in a difficult situation
46. Drink beer, wine, liquor
47. Try to make your own decisions
48. Sleep
49. Say mean things to people; be sarcastic
50. Talk to your father about what bothers you
51. Let off steam by complaining to your friends
52. Talk to a friend about how you feel
53. Play video games, pool, pinball, etc.
54. Do a strenuous physical activity (jogging, biking, etc)

### Family Assessment Device

Nathan B. Epstein, MD, Lawrence M. Baldwin, PhD, Duane S. Bishop, MD

Instructions: This assessment contains a number of statements about families. Read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family.

For each statement there are four (4) possible responses:

Strongly Agree (SA)	Check SA if you feel that the statement describes your family very accurately
Agree (A)	Check A if you feel that the statement describes your family for the most part
Disagree (D)	Check D if you feel that the statement does not describe your family for the most part
Strongly Disagree (SD)	Check SD if you feel that the statement does not describe your family at all

Try not to spend too much time thinking about each statement, but respond as quickly and as honestly as you can. If you have difficulty, answer with your first reaction. Please be sure to answer *every* statement. (**Note** all items were on Survey Monkey with the 4 responses next to the item so the response categories are not included here)

1. Planning family activities is difficult because we misunderstand each other.
2. We resolve most everyday problems around the house.
3. When someone is upset the others know why.
4. When you ask someone to do something, you have to check that they did it.
5. If someone is in trouble, the other become too involved.
6. In times of crisis we can turn to each other for support.
7. We don't know what to do when an emergency comes up.
8. We sometimes run out of things that we need.
9. We are reluctant to show our affection for each other.
10. WE make sure members meet their family responsibilities.
11. We cannot talk to each other about the sadness we feel.
12. We usually act on our decisions regarding problems.
13. You only get the interest of others when something is important to them.

14. You can't tell how a person is feeling from what they are saying.
15. Family tasks don't get spread around enough.
16. Individuals are accepted for what they are.
17. You can easily get away with breaking the rules.
18. People come right out and say things instead of hinting at them.
19. Some of us just don't respond emotionally.
20. We know what to do in an emergency.
21. We avoid discussing our fears and concerns.
22. It is difficult to talk to each other about tender feelings.
23. We have trouble meeting our bills.
24. After our family tries to solve a problem, we usually discuss whether it worked or not.
25. We are too self-centered.
26. We can express feelings to each other.
27. We have no clear expectations about toilet habits.
28. We do not show our love for each other.
29. We talk to people directly rather than through go-betweens.
30. Each of us has particular duties and responsibilities.
31. There are lots of bad feelings in the family.
32. We have rules about hitting people.
33. We get involved with each other only when something interests us.
34. There's little time to explore personal interests.
35. WE often don't say what we mean.
36. We feel accepted for what we are.
37. We show interest in each other when we can get something out of it personally.
38. We resolve most emotional upsets that come up.
39. Tenderness takes second place to other things in our family.
40. We discuss who is to do household jobs.
41. Making decisions is a problem for our family.
42. Our family shows interest in each other only when they can get something out of it.
43. We are frank with each other.
44. We don't hold to any rules or standards.
45. If people are asked to do something, they need reminding.
46. We are able to make decisions about how to solve problems.
47. If the rules are broken, we don't know what to expect.



48. Anything goes in our family.
49. We express tenderness.
50. We confront problems involving feelings.
51. We don't get along well together.
52. We don't talk to each other when we are angry.
53. We are generally dissatisfied with the family duties assigned to us.
54. Even though we mean well, we intrude too much into each others lives.
55. There are rules about dangerous situations.
56. We confide in each other.
57. We cry openly.
58. We don't have reasonable transport.
59. When we don't like what someone has done, we tell them.
60. We try to think of different ways to solve problems.

## Piers-Harris Children's Self-Concept Scale 2

Ellen V. Piers, PhD, Dale B. Harris, PhD, & David S. Herzberg, PhD

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**Directions:**

Here are some sentences that tell how some people feel about themselves. Read each sentence and decide whether it tells the way you feel about yourself. If it is true or mostly true for you, circle the word yes next to the statement. If it is false or mostly false for you, circle the word no. Answer every question, even if some are hard to decide. Do not circle both yes and no for the same sentence.

Remember that there are no right or wrong answers. Only you can tell us how you feel about yourself, so we hope you will mark each sentence the way you really feel inside.

1. My classmates make fun of me
2. I am a happy person
3. It is hard for me to make friends
4. I am often sad
5. I am smart
6. I am shy
7. I get nervous when the teacher calls on me
8. My looks bother me
9. I am a leader in games and sports
10. I get worried when we have tests in school
11. I am unpopular
12. I am well behaved in school
13. It is usually my fault when something goes wrong
14. I cause trouble to my family
15. I am strong
16. I am an important member of my family
17. I give up easily
18. I am good in my schoolwork
19. I do many bad things
20. I behave badly at home
21. I am slow in finishing my schoolwork
22. I am an important member of my class

23. I am nervous
24. I can give a good report in front of the class
25. In school I am a dreamer
26. My friends like my ideas
27. I often get into trouble
28. I am lucky
29. I worry a lot
30. My parents expect too much of me
31. I like being the way I am
32. I feel left out of things
33. I have nice hair
34. I often volunteer in school
35. I wish I were different
36. I hate school
37. I am among the last to be chosen for games and sports
38. I am often mean to other people
39. My classmates in school think that I have good ideas
40. I am unhappy
41. I have many friends
42. I am cheerful
43. I am dumb about most things
44. I am good-looking
45. I get into a lot of fights
46. I am popular with boys
47. People pick on me
48. My family is disappointed in me
49. I have a pleasant face
50. When I grow up, I will be an important person
51. In games and sports, I watch instead of play
52. I forget what I learn
53. I am easy to get along with
54. I am popular with girls
55. I am a good reader
56. I am often afraid
57. I am different from other people
58. I think bad thoughts

59. I cry easily

60. I am a good person



3. Think about the amount of time you spend taking care of your brother or sister with autism.

How happy or unhappy are you with the amount of time you take care of your brother or sister with autism?

Would you like to take more time or less time taking care of your brother or sister with autism?

4. Think about how close you are to your brother or sister with autism.

How happy or unhappy are you with how close you are to your brother or sister with autism?

Would you like to be more close or less close to your brother or sister with autism?

5. Think about the amount of time you and your brother or sister with autism spend playing or doing fun things together.

How happy or unhappy are you with the amount of time you do fun things with your brother or sister with autism?

Would you like to spend more time or less time playing with your brother or sister with autism?

6. Think about how your parents treat you compared to how they treat your brother or sister with autism. This means whether they get mad at you or yell at you or make you do things and how much they do that with your brother or sister with autism.

How happy or unhappy are you with how your parents treat you compared to how they treat your brother or sister with autism?

If you are treated differently, give examples of how they treat you differently.

7. Think about how much you get to be the boss when you are with your brother or sister with autism. This means how much you get to decide what you do together and how much you are the leader and how much you do what your sibling wants.

How happy or unhappy are you with how much you get to be the boss when you are with your brother or sister with autism?

Would you like to be the boss more often or less often than you do now?

8. Think about how much you and your brother or sister with autism are alike. This means that you like to do the same things and that you feel the same way about things most of the time.

How happy or unhappy are you with how much you and your brother or sister with autism are alike?

If you feel that you are alike in some ways, give examples of how you are alike.

9. Think about the attention that you get from your parents. This means how much your parents talk to you, spend time with you, do things for you, and buy things for you.

How happy or unhappy are you with the attention that you get from your parents compared to how much attention your brother or sister with autism gets?

Do you think your parents should start to pay more attention to you or should they start to pay more attention to your brother or sister with autism?

10. All together, how happy or unhappy are you with being your brother or sister with autisms brother or sister?



## Appendix B

### Interactive Autism Network Subject Recruitment Letter

Dear IAN Research participant,

Based on your family profile, one or more members of your family may qualify for the study, below. You should contact the research team directly, using the information provided, if you are interested in joining. You do not have to participate in this study and your non-participation will neither affect the care you receive from any health provider nor your standing as a participant in IAN Research.

*Please note that IAN Research is serving as a resource linking the autism community and researchers. This study is not endorsed by or performed under the auspices of the IAN Research project at Kennedy Krieger Institute/Johns Hopkins.*

**Name of Study:** Adolescent Coping and Perception of Family Functioning in a Family of a Child with Autism

**Location:** University of Michigan School of Nursing

**Eligibility Criteria:** Adolescents 11-20 years of age who have a sibling with autism

**Principal Investigator:** Sally Vliem, MS, RN, CPNP, Doctoral Student University of Michigan School of Nursing

**Contact Information:** Sally Vliem, 269 387-8195

Dear Parent,

I am writing this letter to offer your child(ren) an opportunity to participate in a research study being conducted for my doctoral dissertation. The purpose of this study is to understand, from the adolescent perspective, the experience of having a sibling with autism. The focus of this study will be to examine the coping strategies used by adolescents who have a sibling with autism and to examine how these coping strategies influence their perception of family functioning. This study will also examine if coping strategies and family functioning are influenced by the self concept of the adolescent and the satisfaction with the sibling relationship. This research study will lay a foundation for further intervention research aimed specifically at adolescents and their family to promote positive coping strategies and healthy family functioning.

This study will take 1 hour minimum to complete and will require a computer and access to the internet. The adolescent will be accessing the study using Survey Monkey, a secure, online survey website. If your adolescent is between 18-20 years of age, they may access the site and complete the consent form which will link them to the survey. If your adolescent is 11-17 years of age, you will need to give consent followed by your adolescent giving their assent. The adolescent will be asked about ways they cope with stress, how they perceive that their family is functioning, how they feel about themselves and how they feel about their relationship with their sibling with autism. For their participation, the adolescent will receive a \$10 Amazon e-gift card. There is no charge to participate in the study.

If you are interested in participating, please access the survey at:

[https://www.surveymonkey.com/s.aspx?sm=B8K9IPWkQBW3Xj1bVF2ZPw\\_3d\\_3d](https://www.surveymonkey.com/s.aspx?sm=B8K9IPWkQBW3Xj1bVF2ZPw_3d_3d)

Thank you in advance for your time and assistance. We look forward to working with you in the near future.

Sincerely,

Sally Vliem

Doctoral Candidate

University of Michigan School of Nursing

## Appendix C

### Parental Informed Consent

Your adolescent child may be eligible to take part in a research study. This form gives you important information about the study. It describes the purpose of the study, and the risks and possible benefits for your adolescent who participates in the study.

Please take time to review this information carefully. After you have finished, you may contact the researcher if you have any questions. If you decide to take part in this study, you will be asked to give your consent. *Before you sign this form, be sure you understand what the study is about, including the risks and possible benefits to your adolescent.*

Study Title: Adolescent Coping and Perception of Family Functioning in a Family of a Child with Autism

Person Responsible for Research: Sally Vliem, MS, RN, CPNP, Doctoral Candidate University of Michigan School of Nursing, Dissertation committee, Dr. Loveland-Cherry, Phd, RN, School of Nursing, Dr. Martyn, PhD, RN, School of Nursing, Dr. Darling-Fisher, PhD, RN, School of Nursing and Dr. Chatters, PhD, Health Behavior & Health Education, School of Public Health, School of Social Work

Study Purpose: The purpose of this study is to examine the coping strategies used by adolescent siblings of children with autism and to examine how these coping strategies influence their perception of family functioning. In addition, the self concept of the adolescent will be examined so that the researcher can explore if there is a relationship among self concept and coping strategies that are used by the adolescent. This proposed research study will lay a foundation for further intervention research aimed specifically at adolescents and their family to promote positive coping strategies and a positive perception of family functioning.

If you are the parent of an adolescent who meets the following criteria, your adolescent's participation is welcome. If you have more than one child who meets the eligibility criteria, all may participate. A minimum of 92 adolescents is being sought to participate in this study. Inclusion criteria include:

- Age 11-20 years of age
- Older sibling of a child with autism
- Sibling with autism must be diagnosed with an autism spectrum disorder
- Sufficient command of the English language (both reading and writing) so testing can occur
- Have access to a computer with internet access

If you give permission for your adolescent to participate in this study, they will be asked to complete a survey on line at the Survey Monkey website. Your adolescent will be asked about ways that they cope with stress, how they perceive that their family is functioning, how they feel about themselves and how they feel their relationship is with their sibling with autism. All the survey instruments have been used with the adolescent population. In addition, background information will be obtained including child's age, sex, hours spent in caregiving, and advantages and challenges of living with a sibling with autism. The survey will take approximately 45-60 minutes to complete. The survey can be stopped and restarted if your adolescent becomes fatigued.

**Risks/Benefits:** The risks of participation are minimal for completing the instruments and may be limited to the adolescent becoming mildly upset when thinking about their sibling with autism. Parents or guardians are encouraged to be home while the adolescent is completing the survey but to ensure the adolescent's privacy while they are completing the survey. While no direct benefits to the participants will be identified at this time, the knowledge gained from this study could lead to interventions that will assist adolescents to cope more effectively and improve their perception of family functioning. Participation in the study could raise the adolescent's awareness of the coping strategies that they use and how they perceive their family functioning from an objective perspective. As more is known about how adolescents who have a sibling with autism cope and how they perceive that their family is functioning, interventions can be designed to promote active coping strategies and improve the health of families who have children with autism. Each adolescent who completes the survey will receive a \$10 iTunes gift card for their participation.

**Confidentiality:** Your adolescent's responses are completely confidential and no individual participant can be identified with his/her answers. Data from this study will be stored on the researcher's password protected computer to allow for analysis of the data.

**Voluntary Participation:** Your adolescent's participation in this study is voluntary. You may choose to not allow them to participate or to have them terminate their survey at any time without penalty. If you agree to allow your adolescent to participate, you will be linked to the survey site and your adolescent will be able to complete the survey at their convenience.

Who do I contact for questions about my rights or complaints towards my treatment as a research subject?

You may contact the principal investigator at:

Sally Vliem, MS, RN, CPNP, University of Michigan doctoral candidate  
Western Michigan University Bronson School of Nursing  
1903 W. Michigan Ave  
Kalamazoo, MI 49008  
269 580-3737

You may also express a concern about a study by contacting the Institutional Review Board listed below or by calling the University of Michigan Compliance Help Line at 1-888-296-2481.

University of Michigan IRB Health Sciences  
University of Michigan IRB Behavioral Sciences  
540 East Liberty  
Suite 202  
Ann Arbor, MI 48104  
Telephone: (734) 936-0933  
Fax: (734) 998-9171  
e-mail: [irbhsbs@umich.edu](mailto:irbhsbs@umich.edu)

Parental consent for your adolescent to participate in research: Indicating agreement to allow your adolescent to participate in this research project indicates that you have read this consent and have had all of your questions answered, and that you are 18 years of age or older. If your adolescent is 18-20, they may agree to give consent and continue on to the survey. If your adolescent is 11-17, they will need to give assent for their participation before being linked to the survey.

## Adolescent Assent Form

Title: Adolescent Coping and Perception of Family Functioning in a Family of a Child with Autism

Protocol No.: HUM00023386

Sponsor: University of Michigan

Investigator: Sally Vliem

Sub-Investigators: Dissertation committee, Dr. Loveland-Cherry, PhD, RN, School of Nursing, Dr. Martyn, PhD, RN, School of Nursing, Dr. Darling-Fisher, PhD, RN, School of Nursing and Dr. Chatters, PhD, Health Behavior & Health Education, School of Public Health, School of Social Work

The investigators named above are doing a research study.

**These are some things we want you to know about research studies:**

We are asking you to be in a research study. Research is a way to test new ideas. Research helps us learn new things.

Whether or not to be in this research is your choice. You can say Yes or No. Whatever you decide is OK.

**Why am I being asked to be in this research study?**

You are being asked to be in the study because you have a younger brother or sister with autism.

**What is the study about?**

This study will help us understand what it is like to have a brother or sister with autism. This study will help us understand how you deal with stress, how you feel your family works together, how you feel about yourself, and how you feel about your sibling with autism, and the good and bad things about having a brother or sister with autism.

**What will happen during this study?**

You will be using the computer to answer some questions about how you deal with stress, how you feel your family works together, how you feel about yourself, and how you feel about your brother or sister with autism.

The computer survey will take 1 hour minimum to complete. You can stop the survey and restart it at any time. Please complete the survey by yourself, but, if you become tired or upset and need to talk with a parent or guardian that is OK. When you have completed the entire survey, you will get a \$10 Amazon gift certificate for participating.

**What else should I know about the study?**

If you feel upset about the questions that are asked, you may stop the survey and finish it later or you may choose to not finish the study at all. If you need to talk with a parent or guardian while working on the questions you may stop the survey and speak with your parent.

**What are the good things that might happen?**

People may have good things happen to them because they are in a research study. These are called “benefits.” You will be helping us understand what it is like to have a brother or sister with autism and help us find ways to make things that are not going well go better.

**What if I don’t want to be in this study?**

You do not have to be in the study if you do not want to. You may stop answering questions at any time. No one will be mad at you if you don’t want to do this.

**Who should I ask if I have any questions?**

If you have any questions about this study, you or your parents or guardian can call:

You may contact the principal investigator at:  
Sally Vliem, MS, RN, CPNP, University of Michigan doctoral candidate  
Western Michigan University Bronson School of Nursing  
1903 W. Michigan Ave  
Kalamazoo, MI 49008  
269 387-8195

You may also express a concern about a study by contacting the Institutional Review Board listed below or by calling the University of Michigan Compliance Help Line at 1-888-296-2481.

University of Michigan IRB Health Sciences  
540 East Liberty

Suite 202  
Ann Arbor, MI 48104  
Telephone: (734) 936-0933  
Fax: (734) 998-9171  
e-mail: [irbhsbs@umich.edu](mailto:irbhsbs@umich.edu)

The researchers have told me about the research. I had a chance to ask questions. I know I can ask questions at any time. I want to be in the research.

If you agree to answer these questions, you will be linked to the beginning of the survey. If you decide not to participate you will be linked to the exit of the survey.



### 18-20 Year Old Consent Form

You may be eligible to take part in a research study. This form gives you important information about the study. It describes the purpose of the study, and the risks and possible benefits of your participating in the study.

Please take time to review this information carefully. After you have finished, you may contact the researcher if you have any questions. If you decide to take part in this study, you will be asked to give your consent. *Before you sign this form, be sure you understand what the study is about, including the risks and possible benefits to your adolescent.*

Study Title: Adolescent Coping and Perception of Family Functioning in a Family of a Child with Autism

Person Responsible for Research: Sally Vliem, MS, RN, CPNP, Doctoral Candidate University of Michigan School of Nursing, Dissertation committee, Dr. Loveland-Cherry, Phd, RN, School of Nursing, Dr. Martyn, PhD, RN, School of Nursing, Dr. Darling-Fisher, PhD, RN, School of Nursing and Dr. Chatters, PhD, Health Behavior & Health Education, School of Public Health, School of Social Work

Study Purpose: The purpose of this study is to understand, from the adolescent perspective, the experience of having a sibling with autism. The focus of this study will be to examine the coping strategies used by adolescents who have a sibling with autism and to examine how these coping strategies influence their perception of family functioning. This study will also examine if coping strategies and family functioning are influenced by the self concept of the adolescent and the satisfaction with the sibling relationship. The amount of time spent in care taking activities will also be explored. This research study will lay a foundation for further intervention research aimed specifically at adolescents and their family to promote positive coping strategies and healthy family functioning.

If you are an adolescent who meets the following criteria, your participation is welcome. A minimum of 92 adolescents is being sought to participate in this study. Inclusion criteria include:

- Age 11-20 years of age

- Sibling with autism must be diagnosed with an autism spectrum disorder
- Sufficient command of the English language (both reading and writing) so testing can occur
- Have access to a computer with internet access

If you give your permission to participate in this study, you will be asked to complete a survey on line at the Survey Monkey website. You will be asked about ways that you cope with stress, how you perceive that your family is functioning, how you feel about yourself and how you feel about your relationship with your sibling with autism. All the survey instruments have been used with the adolescent population. In addition, background information will be obtained including your age, sex, hours spent in care giving, and advantages and challenges of living with a sibling with autism. The survey will take approximately 1 hour minimum to complete. The survey can be stopped and restarted if you become tired.

**Risks/Benefits:** The risks of participation are minimal for completing the instruments and may be limited to you becoming mildly upset when thinking about your sibling with autism. If your parents or guardians are present while you complete the survey, please ask them to allow you privacy while you complete the survey. While no direct benefits to you will be identified at this time, the knowledge gained from this study could lead to interventions that will assist adolescents to cope more effectively and improve the health of their family. Participation in the study could raise your awareness of the coping strategies that you use and how you perceive your family functioning from an objective perspective. As more is known about how adolescents who have a sibling with autism cope and how they perceive that their family is functioning, interventions can be designed to promote active coping strategies and improve the health of families who have children with autism. Each adolescent who completes the survey will receive a \$10 Amazon gift card for their participation.

**Confidentiality:** Your responses are completely confidential and no individual participant can be identified with his/her answers. Data from this study will be stored on the researcher's password protected computer to allow for analysis of the data.

**Voluntary Participation:** Your participation in this study is voluntary. You may choose to not participate or to terminate your survey at any time without penalty. If you agree to participate, you will be linked to the

survey site and you will be able to complete the survey at your convenience.

Who do I contact for questions about my rights or complaints towards my treatment as a research subject?

You may contact the principal investigator at:

Sally Vliem, MS, RN, CPNP, University of Michigan doctoral candidate  
Western Michigan University Bronson School of Nursing  
1903 W. Michigan Ave  
Kalamazoo, MI 49008  
269- 387-8195

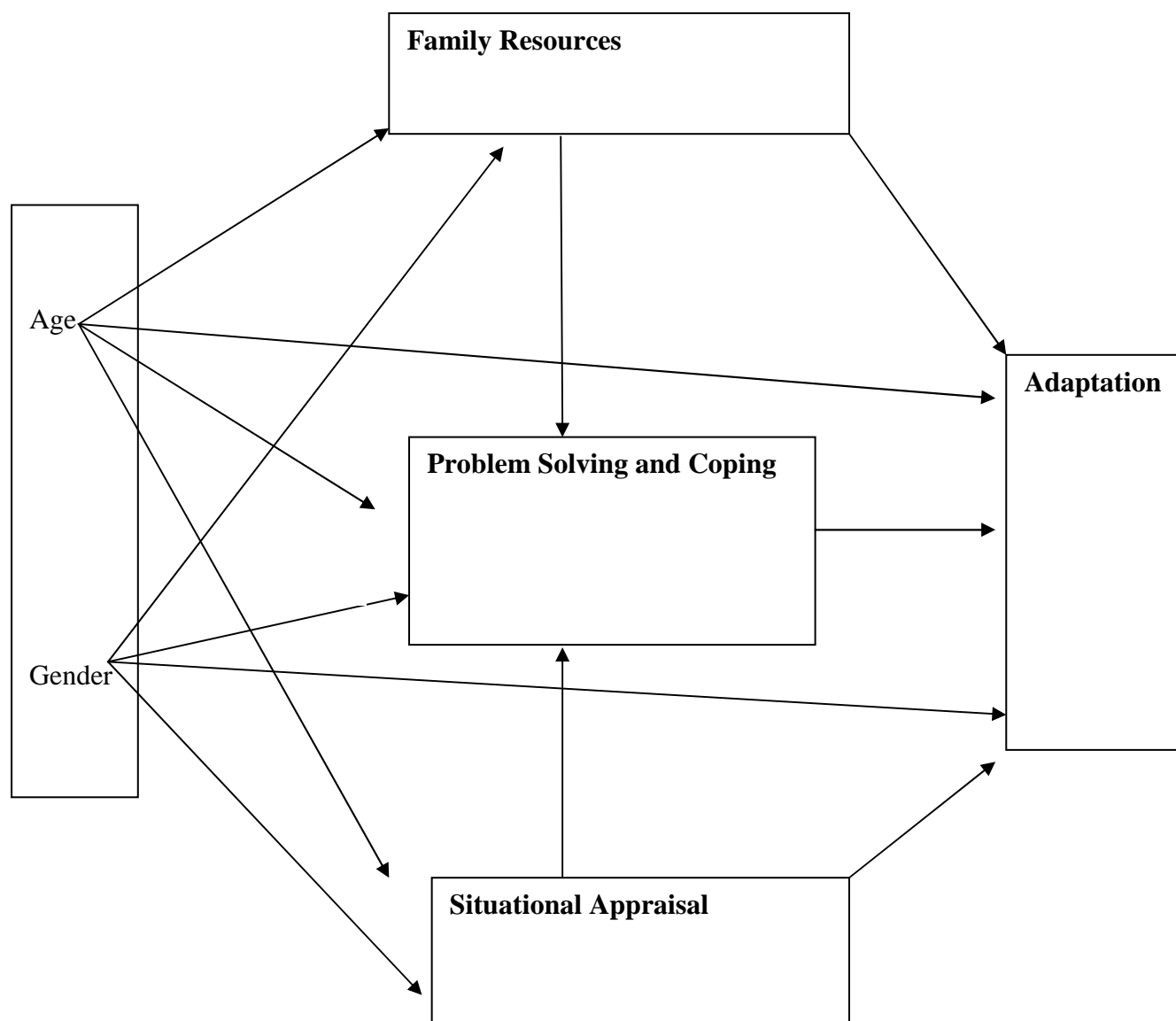
You may also express a concern about a study by contacting the Institutional Review Board listed below or by calling the University of Michigan Compliance Help Line at 1-888-296-2481.

University of Michigan IRB Health Sciences  
540 East Liberty  
Suite 202  
Ann Arbor, MI 48104  
Telephone: (734) 936-0933  
Fax: (734) 998-9171  
e-mail: [irbhsbs@umich.edu](mailto:irbhsbs@umich.edu)

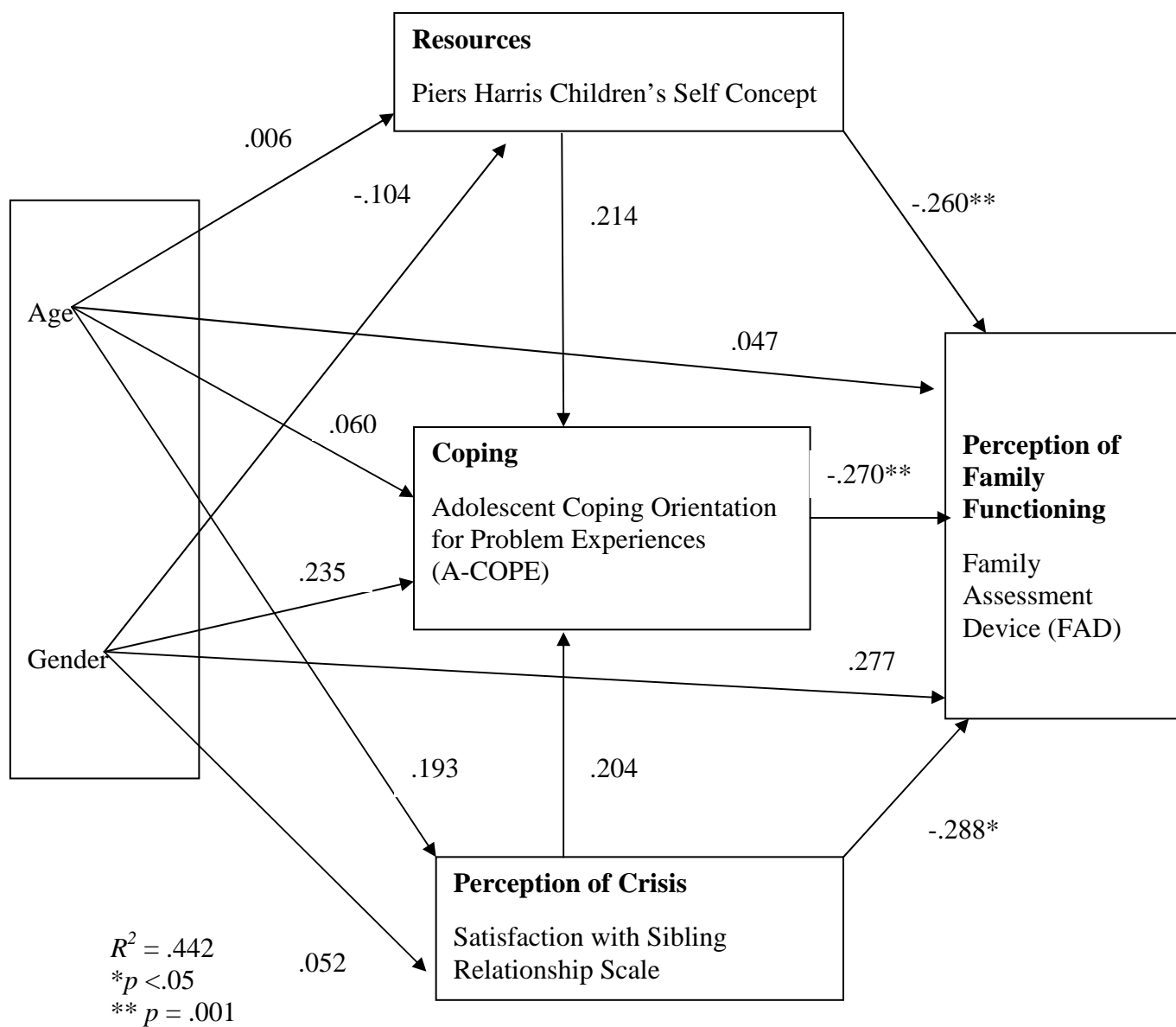
The researchers have told me about the research. I had a chance to ask questions. I know I can ask questions at any time. I want to be in the research.

If you agree to answer these questions, you will be linked to the beginning of the survey. If you decide not to participate you will be linked to the exit of the survey.

## Appendix D

*Resiliency model of stress, adjustment, and adaption*

*Path analysis for model*



## Appendix E

*Demographic Characteristics of Sample*

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## Age

Mean (SD)	Range
14.3 years (2.41)	11-19 years

## Sibling age

Mean (SD)	Range
10.8 years (3.95)	3-18 years

## Race

Caucasian	n=85 (87.6%)
African American	n=1 (1%)
Hispanic	n=7 (7.2%)
Asian	n=1 (1%)
Other	n=2 (2.1%)

## Gender

Male	n=22 (22.7%)
Female	n=31 (32%)

## Gender sibling with autism

Male	n=80 (82.5%)
Female	n=16 (16.5%)

## Other siblings

Yes	n=60 (61.9%)
No	n=36 (37.1%)

## Family living with you

Mother	n=95 (97.9%)
Father	n=71 (73.2%)
Stepmother	n=1 (1%)
Stepfather	n=13 (13.4%)
Grandmother	n=7 (7.2%)
Grandfather	n=2 (2.1%)
Brother	n=42 (43.3%)
Sister	n=36 (37.1%)
Sibling with autism	n=92 (94.8%)

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*A-COPE Subscale Frequencies, Measures of Central Tendency, Skew, Kurtosis, and Reliability*

Subscale	n	Mean	SD	Skew	Kurtosis	$\alpha$
Ventilating feelings	94	16.70	4.53	.238	.102	.69
Seeking diversions	92	21.72	3.91	-.482	.241	.40
Self reliance & optimism	93	17.88	3.85	-.054	.441	.66
Social support	92	18.50	4.03	-.130	.238	.54
Solving family problems	93	17.00	4.45	-.080	-.258	.75
Avoiding problems	91	8.09	1.99	1.056	2.414	.31
Spiritual support	95	5.58	2.83	1.064	.458	.79
Investing in close friends	94	17.00	1.98	.254	-.349	.46
Professional support	95	3.03	1.52	1.676	2.404	.57
Demanding activity	95	11.36	3.32	-.007	-.275	.72
Being humorous	96	6.42	2.21	-.312	-.752	.81
Relaxing	94	12.15	2.98	-.078	-.380	.52
Entire Scale						.85

*Levene's test for A-COPE subscales and total scale*

Subscale	Levene's Test for Equality of Variance	
	F	Significance
Ventilating feelings	1.054	.309
Seeking diversion	.620	.435
Seeking social support	.061	.806
Avoiding problems	3.422	.071
Spiritual support	1.499	.227
Investing in friends	5.003	.030
Professional support	3.440	.069
Demanding activity	.386	.537
Being humorous	.409	.525
Relaxing	.002	.964
Total scale	1.298	.261



*Early, Middle, and Late Adolescent Groups*

	Age	Frequency	Percent
Early Adolescence	10-11	25	25.8%
Middle Adolescence	12-16	50	51.5%
Late Adolescence	17-20	21	21.6%
Missing Data		1	1%

*FAD Subscale Frequencies, Measures of Central Tendency, Skew, Kurtosis, and Reliability*

Subscale	n	Mean	SD	Skew	Kurtosis	$\alpha$
Problem solving	92	2.24	.546	.676	.788	.83
Communication	92	2.25	.472	.048	-.076	.79
Roles	89	2.32	.426	-.200	-.571	.77
Affective responsiveness	93	2.15	.588	.454	.518	.82
Affective involvement	92	2.25	.538	.121	-.055	.79
Behavioral control	91	1.78	.423	.064	-.482	.77
General functioning	92	2.04	.550	.987	1.419	.90

*FAD subscale means and cut-off scores for healthy family functioning*

Subscale	Mean	Cut-off scores for healthy family functioning
Problem solving	2.24	2.20
Communication	2.25	2.20
Roles	2.32	2.30
Affective responsiveness	2.15	2.20
Affective involvement	2.25	2.10
Behavioral control	1.78	1.90
General functioning	2.04	2.00