

THE RELATIONSHIP BETWEEN RESOURCES AND SENSE OF COHERENCE IN
ADOLESCENT SIBLINGS OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

By
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In Memory of My Mother
Virginia Helene Oosterbaan
(nee Boot)

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Abstract of Dissertation Presented to the Graduate School
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DISORDER

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Research involving sibling dyads, particularly those in which one of the siblings has a disability, is of vital importance to health care providers because of the integral role family members play in providing, promoting and protecting the needs of their disabled constituent. Furthermore, inconsistent adjustment scores have been identified in siblings of individuals with an autism spectrum disorder. This study aimed to characterize adolescent siblings of persons with autism, Pervasive Developmental Disorder-Non-Specified (PDD-NOS), and Asperger's syndrome by describing their sense of coherence, coping strategies, relationship networks, and psychological well-being from self-reporting instruments. A secondary aim was to test the theoretical framework of Aaron Antonovsky's (1987) Stress, Health & Coping: A model of Salutogenesis.

Parents provided consent and completed a demographic survey and the Childhood Autism Rating Scale, 2nd Edition. Sibling assent yielded a sample of adolescent siblings (N=96). Data were obtained using: Network of Relationship Questionnaire – Social Provision Version; Adolescent Coping Orientation for Problem Experiences; Youth Self Report; and Sense of Coherence. Sibling demographics were

related to scale scores of each instrument providing rich descriptions of this adolescent group. ASD severity was analyzed as a predictor of sibling coherence and each sibling resource. Mediating and moderating variables were used to test the model in hierarchical regression models.

Consistent with previous research, sibling age and gender contributed 8% of the variance to the model. Females ($t = 2.88, p < .01$) and older siblings ($t = 2.17, p < .05$) perceived more supportive relationships with their brother/sister on the autism spectrum. There was an indirect relationship ($r = -.154, p = .10$) between sibling age and SOC scores, suggesting that it may become more difficult to manage as siblings' age. This adolescent group reported the greatest amount of support came from parents, followed by friends and siblings respectively. An indirect effect was identified and siblings with a greater number of problems had lower SOC scores regardless of ASD severity. Furthermore, sibling coping strategies interacted with ASD severity, suggesting siblings need more coping strategies to manage when there are high levels of ASD severity. Findings support the need for future intervention studies.

CHAPTER 1 INTRODUCTION

Research involving sibling dyads, particularly those in which one of the siblings has a disability, is of vital importance to health care providers because of the integral role family members play in providing, promoting and protecting the needs of their disabled constituent. Social interactions within the family environment impact the child's cognitive and emotional state (Kim, McHale, Crouter & Osgood, 2007; Vygotsky, 1978). These early perceptions provide operative frameworks that are used for self-identification and impact sibling interactions (Branje, van Lieshout, van Aken & Haselager, 2004; Raley, 2001). As a result, the typically developing sibling acquires internal and external resources to adapt to the challenges presented by the disability. It is necessary to identify resources that influence sibling adaptation in order to facilitate their adjustment and enhance conditions for all members within the family environment.

According to the Centers for Disease Control (CDC) 2010 statistics, 1.5 million people in the United States have an Autism Spectrum Disorder (ASD). Families of children with ASD are faced with complex adjustment and care demands that present significant challenges to all family members including siblings. In research comparing behavioral adjustment and relationship quality among siblings of persons with ASD to persons with Down's syndrome, cerebral palsy and typical siblings, siblings of a person with ASD were found to have greater difficulty adjusting (Meaden, Stoner, & Angell, 2010; Orsmond & Seltzer, 2007b; Stoneman, 2001).

Problem

A review of the sibling literature identifies inconsistencies among studies and these inconsistencies make it difficult to identify siblings who may be vulnerable to poor

adjustment outcomes. Researchers continue to investigate the family system, sibling resources, and biologic markers to explain why siblings of individuals with ASD may be at greater risk for adjustment disorders. The unique challenges associated with sibling adjustment are thought to be related to hallmarks of the ASD disability, which include difficulty communicating, inappropriate social behaviors, and the absence of physical disfigurement (Hastings, Kovshoff, Ward, delgi Espinosa, & Remington, 2005; Lobato & Kao, 2002; Fisman Wolf, Ellison & Freeman, 2000). There are indications that early involvement of siblings in the care of their brother/sister with ASD has a positive impact on both sibling groups (Blacher & Begum, 2009; Hodopp & Urbano, 2007; Maynard & Martini, 2005; Orsmond, Kuo & Seltzer, 2009). Despite correlates of parental characteristics and a genetic phenotype to sibling adjustment, specific sibling resources that are utilized remain unclear.

Given the rising prevalence (CDC, 2010), complex nature of autism, and inconsistencies of sibling adjustment, it is critically important to characterize typically developing (TD) siblings of individuals with ASD. Studies have evolved from descriptive designs correlating gender, birth order and age of siblings with ASD and other disability types to exploratory designs investigating personality traits. In the proposed study, the Salutogenesis Model (Antonovsky, 1987) is used as the theoretical framework to guide the research.

Study Aims

This dissertation study has two aims: 1) characterize adolescent siblings of individuals with an Autism Spectrum Disorder (ASD) through a description of demographic data, coping strategies, social support, psychological well-being, and life orientation; 2) test the Salutogenesis Model by Antonovsky (1987) via correlation and

regression analyses to determine the association of resources on the relationship between ASD severity and sibling coherence levels.

Theoretical Foundation

Aaron Antonovsky's (1987) *Stress, Health & Coping: A Salutogenesis Model* was used as a theoretical framework to guide the investigation (Fig 1-1). The model has sociologic roots and has received empirical support in adolescent populations (Antonovsky & Sagy, 1986; Margalit & Eysenck, 1990). A substructured model (Fig. 1-2) includes three conceptual relationships – stress, resource, and coherence - and these will be operationalized to test the model. The concept of coherence is the dependent variable and is defined as a life orientation or personal disposition. The Sense of Coherence (SOC) instrument (Antonovsky, 1987) measures the ability of a person to stay well under difficult environments. It is used in the study to relate sibling resources (coping strategies, relationship quality, and psychological well being) and stress (ASD severity). The following discussion is a brief summary of the model's theoretical foundation.

A salutogenic approach, translated from the Latin derivatives *salut* (happy) and *genesis* (beginning), answers the question, “What keeps an individual healthy?” Through this orientation, investigators search for ways individuals effectively adapt. The approach “moves beyond a Cartesian dualism of ‘disease and cure’ and looks to imagination, love, play...and the social structures that foster them” (Antonovsky, 1987 p. xv). Individual cases of normal adjustment under stressful conditions are examined to determine what contributes to this disposition.

According to the theory, tension, a byproduct of the stressor, is indirectly related to the individual's life orientation as measured by the SOC instrument. SOC levels differ

among individuals because there is variation in their *generalized resistive resources* (GRR) and psychosocial stressors, or *generalized resistive deficits* (GRD). These independent factors, resistive resources and resistive deficits, are combined into one concept referred to as the GRR-RD (Antonovsky, 1987). Successful management of the stressor is anticipated for individuals with high SOC levels.

The theory of Salutogenesis rejects the view that people are either healthy or sick. Instead, it asserts that an individual's health, the model's outcome variable, is on a continuum. Persons naturally migrate to the wellness end of the continuum and this movement is referred to as "negative entropy" (Antonovsky, 1987 p. 19). When individuals participate in the social system and the physical environment, they counteract the inconsistency related to the stress, which helps them maintain their balance. A change in their position on the health continuum is influenced by an individual's SOC level. In the model, a recursive relationship exists between SOC levels and resources. A person's available resources influence the development of his/her SOC levels beginning in childhood through early adulthood and then his/her SOC levels stabilize. According to the theory, when tension is created by the stressor, the individual's SOC level mobilizes the resources necessary to manage it (Antonovsky, 1987).

The salutogenic model is a coping theory and used in health promotion research. There are three major assumptions: (a) heterostasis and disorder are a usual occurrence throughout life, with internal and external factors assisting the organism to achieve homogeneity and balance; (b) a person's SOC levels is a measure of their

outlook of the world as ordered, predictable, and manageable; and, (c) resources not identified in the literature require a qualitative investigation (Antonovsky, 1987).

When an individual understands the stressor, finds the necessary resources to manage it, and has an emotional investment in adjusting to it, his/her health can remain stable under stressful life conditions. Thus, the researcher identifies resources that maintain an individual's location on the health continuum instead of focusing on the stressor. In this study, SOC scores will be described for adolescent siblings of individuals with ASD. To examine the model, sibling coping strategies, social support, and psychological well being are correlated to ASD severity (stress) and Sense of Coherence levels.

Salutogenesis Model and the Nursing Metaparadigm

The TD adolescent siblings of individuals with ASD have an atypical family environment where routines, expenses, and caretaking are greater concerns in comparison to other adolescent sibling groups. These influences must be evaluated for each individual family member. The health care community is often the first place that family members of persons with ASD present for treatment and care (Twoy Connolly, & Novak, 2006). Therefore, nurses and other health professionals have a responsibility to evaluate the environment of individuals with ASD in order to promote optimal health within the family environment.

The sociologic framework of Salutogenesis is appropriate for discovering resources within the environment that can be utilized by the typically developing adolescent sibling to manage stress related to ASD. Nurses can play an instrumental role by understanding and promoting the necessary resources to provide greater meaning, comprehension, and manageability of the stressor (ASD). The theoretical

concepts used in the proposed study and their relationships are discussed in the next section.

Stress, Resource, and Sense of Coherence

Stress

It occurred to Antonovsky (1979) that not *all* stress was detrimental. In fact, it became clear to him that people who overcame stressful situations had different dispositions and strengths in their characters than individuals who succumbed to it. Antonovsky's early work was not initially popular because it posited that there is physiologic evidence for successful stress management (resilience). Today, Antonovsky's (1987) salutogenic model is recognized by many stress researchers and supports a paradigm shift in neurobehavioral science.

Medical anthropologists consider the psychological, sociological and biological influences on the identified stressor and assert that these influences cannot be taken out of context (Weisner, 2005; Wiley & Allen, 2009). In this study, the family environment influences typically developing siblings of individuals with ASD and this social context creates an impact and contributes to the challenges of isolating and identifying resources used in tension management. The sibling's gender, age, birth rank (younger/older), sibling age difference, and family size are demographic variables that will be explored in relation to study variables and reported to describe siblings of individuals with ASD.

Studies indicate that in families in which one member has ASD, severity of the ASD and difficult behavior in particular, were associated with higher levels of perceived stress in parents, caregivers, and siblings (Lecavalier, Leone, & Wiltz, 2006; Davis & Carter, 2008; Schieve, Blumberg, Rice, Visser & Boyle, 2008). In addition, several

researchers found an association between parents' stress levels and increased anti-social behaviors in typically developing siblings (Mugno, Ruta, D'Arrigo & Mazzone, 2007; Lewis et al., 2006). In the current study, *stress* is operationalized by the severity score of ASD measured by the Children with Autism Rating Scale- 2nd Edition (CARS-2; Schopler, Van Bourgondien & Love, 2010). The relationship of ASD severity to each adolescent sibling's generalized resistive resources – resource deficit (GRR-RD) and his or her SOC levels was examined.

Resources

A resource is defined as a reserve supply of an adaptive quality, and/or adeptness at finding solutions to the stressor. The type of resource impacts the adolescent sibling by serving as a functional learning system that influences the process of his or her development (Moshman, 2005). Parental characteristics, family environments, and sibling variables have been investigated to differentiate siblings of individuals with ASD from other siblings (Smith & Elder, 2010). Inconsistencies in the data and the limited number of studies substantiate the need for further research. The resources in the study include adolescent sibling report of social support, coping strategies, and psychological well being. Previous investigators have examined these variables through parental report in relation to sibling adjustment (Gavidia-Payne, 2006; Mugno, et al., 2007; Rivers & Stoneman, 2003). Further investigation through sibling self-report contributes to the characterization of siblings of individuals with ASD.

Psychological Well being. Previous studies (Glasberg, 2000; Kaminsky & Dewey, 2001; Orsmond et al., 2009; Pilowsky, Yirmiya, Doppelt, Gross-Tsur & Shalev, 2004; Rivers & Stoneman, 2003; Ross & Cuskelly, 2006) have found correlations between sibling adjustment levels and sibling coping style, social support, competence,

self-concept, relationship quality, and knowledge of the ASD. Adjustment was measured using the Child Behavior Checklist (CBCL; Achenbach, 1991). Several investigators have reported higher levels of internalizing (anxiety and depression) and externalizing (conduct disorders, aggression, and antisocial) behaviors in siblings of individuals with ASD compared to siblings of other types, although these findings are not consistent across studies (Kim, McHale, Crouter, & Osgood, 2007; Orsmond & Seltzer, 2007).

Relationship networks. Research regarding the relationship quality of siblings has primarily focused on the interaction between the typically developing (TD) sibling and his/her brother/sister with ASD. Different instruments have been used among studies but they were all designed to measure the quality of a relationship in a usual sibling dyad and not a relationship where one member has a disability. Researchers have reported that siblings of individuals with ASD have similar or more favorable relationship quality than siblings without a disabled family member. Relationship characteristics include high levels of admiration, tolerance, empathy, and selflessness and low levels of quarreling and competition (Ross & Cuskelly, 2006; Verte, Roeyer, & Buysee, 2003). Their data suggest that siblings of individuals with ASD have adequate relationships and may have greater adaptive ability than siblings without a disabled family member (Stoneman, 2001; Ferraioli & Harris, 2010).

Two other studies investigated social support for siblings of persons with ASD (Rivers & Stoneman, 2003; Bayat, 2007). The adolescent literature review found empirical evidence that adolescents reported a preference for peer support over parental support (Scholte, Engels, deKemp & Overbeek, 2007; Stice, Ragan, and

Randall, 2004). In consideration of this, the Network of Relationship Inventory-Social Provision Version (NRI-SPV; Furman & Buhrmester, 2009) was selected for this study. It measures support, conflict and relative power between the TD adolescent sibling and one parent, brother/sister with ASD, and a friend. The support scale for each individual was correlated to ASD severity and sibling SOC levels and entered into the hierarchical regression model. Predictive variables were examined for an indirect (mediating) or interaction (moderating) effect using hierarchical regression to control for sibling age and gender. In addition, each scale variable was examined in separate regression model to determine if they had an interaction with ASD severity to moderate the relationship between ASD severity and sibling SOC scores.

Coping strategy. The sibling's perception of stress related to the ASD determines its impact on him/her (Bishop, Reichler, Cain & Lord, 2007) and the coping strategy employed (Antonovsky, 1987; Lazarus, 1990; McCubbin & Patterson, 1983). For example, one sibling may report hiding his feelings to avoid disruption or conflict within the family while another sibling may act out to gain attention (Hutson & Alter, 2007; Ferraioli & Harris, 2010). Furthermore, the life course of development, including the period of adolescence, influences the sibling's selection of a coping strategy (Bjorkland, 2005).

Adolescence, according to Erikson (1969), is the stage of identity formation. This lifetime process begins in the second decade of life and drives an individual's emotions and behaviors that contribute to his/her psychosocial adjustment (Moshman, 2005; Ratey, 2001). The Adolescent Coping Orientation for Problem Experiences (A-COPE; Patterson & McCubbin, 1987) was used to measure coping strategies used by TD

siblings. Total scores were correlated to the ASD severity and TD sibling SOC levels. The coping strategy total score was then tested as a mediating and moderating variable.

Sense of Coherence

The dependent variable in the proposed study is the TD sibling's life orientation, or disposition, and this is measured using the sense of coherence (SOC) instrument (Antonovsky, 1987). The SOC is comprised of three components - *meaningfulness*, *manageability*, and *comprehension* - and each component is influenced by the individual's culture, history and social structure. To provide further clarity for the SOC concept, the following discussion is provided.

Comprehension is a component of the SOC and derived from a person's cognitive ability. Thus, an individual with a high level of comprehension can make sense of the stressor, explain it, and know what to expect. *Manageability* refers to the adequate access to necessary resources, thereby enabling an individual to deal with the stressor. Antonovsky (1987) reports that persons with high manageability SOC scores look at untoward events as 'part of life' rather than viewing themselves as a 'victims' under the circumstances. The final component of the SOC, *meaningfulness*, is defined as an individual's motivational level. Unlike comprehension, this component does not require the person to have a full understanding of the stressor; rather, he/she has enough information to bring about an emotional investment. The person's willingness to act on the stressor is almost always the result of the value society places on the stressor (Antonovsky, 1987).

The amount of meaning, manageability, and comprehension varies among individuals but the levels for each are intertwined; thus, they cannot be separated from

the total SOC score. Individual resources influence all three components but not to the same degree (Antonovsky, 1987). An individual's resource and stress levels can predict the SOC in the Salutogenic Model. The present study tests the model by statistically analyzing the relationships between stress, resources and SOC levels in TD adolescent siblings of individuals with ASD.

Research Questions

1. Are demographic variables of age, gender, birth rank, family size, and age difference of typically developing siblings of individuals with an autism spectrum disorder (ASD) related to their coping strategies (A-COPE), social support networks (NRQ-SPV), psychological well being (YSR), and life orientation (SOC) scores?
2. Do siblings of individuals with ASD perceive greater levels of support from parents, friends, or siblings on the autism spectrum?
3. Do coping strategies, relationship network, and psychological well being scores correlate with ASD symptom severity as measured on the Child Autism Rating Scale – 2nd Ed. (CARS-2) and life orientation as measured on the sense of coherence instrument (SOC) in typically developing, adolescent siblings of persons with ASD?
4. Is the typically developing sibling resource (coping, support, or psychological well being) a mediating or moderating variable between the association of ASD severity and typically developing sibling SOC levels?

Summary

This chapter has provided a general background for the study and the research aims. The theoretical framework of Stress, Health & Coping: A Salutogenesis Model guides the investigation (See Figure 1-1) and is explained as it relates to a nursing meta-paradigm. Conceptual and operational definitions are detailed for each major construct – stress, sibling resources, and sense of coherence. A brief reference to background evidence for the study hypotheses is also presented along with the research questions.

A review of the literature of siblings of individuals with ASD follows in the next chapter and describes the concepts of stress, psychological well-being, coping, social support, and sense of coherence in prior research.

Salutogenic Model

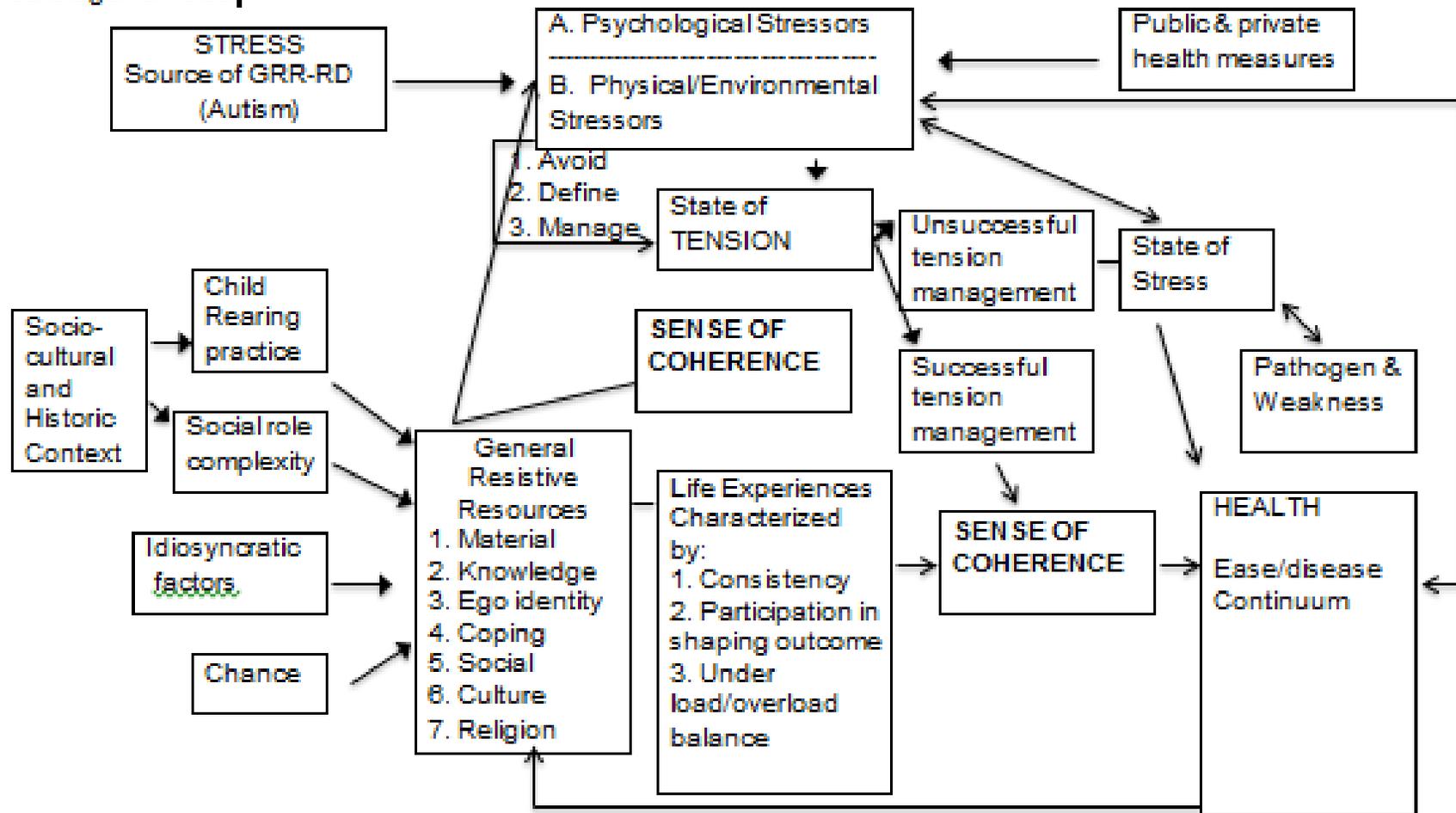


Figure 1-1. Theoretical framework by Aaron Antonovsky (1979), Adapted from "Health, Stress & Coping: The Salutogenic Model of Health"

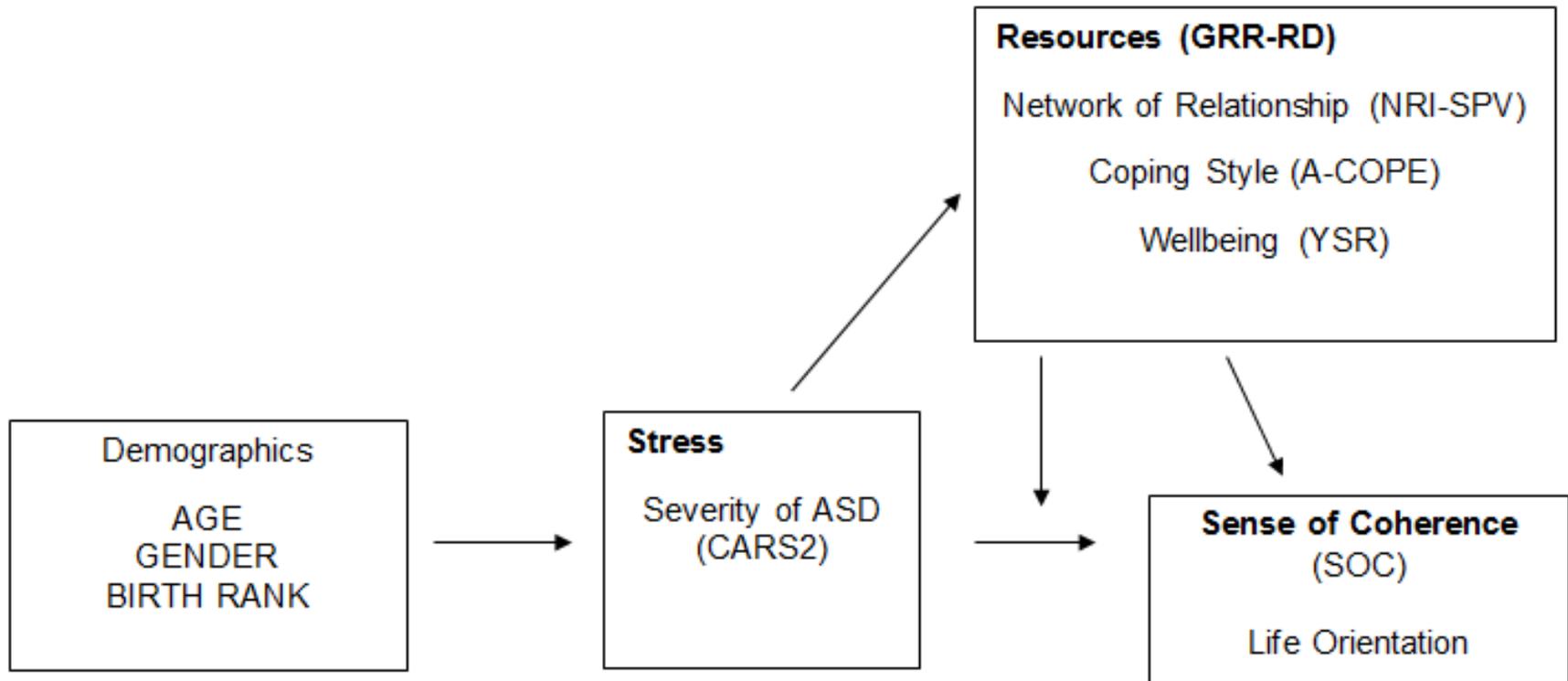


Figure 1-2 Model for current study

CHAPTER 2 A REVIEW OF THE LITERATURE

The aim of this dissertation study is to characterize the typically developing (TD) adolescent sibling of individuals with Autism Spectrum Disorder (ASD). In this chapter, a review of the sibling literature of individuals with ASD is divided into three sections. In the first section, ASD severity and behaviors are described as operative definitions of stress in the research study. Next, sibling resources of individuals with ASD are identified in previous investigative work. The final section explains the life orientation concept and the sense of coherence (SOC) instrument (Antonovsky, 1987).

The Diagnostic Statistical Manual of Mental Disorders-Revised (DSM-IV-R) describes core features of ASD including alterations in communication, cognition, and behaviors (American Psychiatric Association; APA, 2006). Speech and/or language impairment, problems interacting with others, and heightened sensory stimulation are symptoms of the disability, exhibited in children before they reach 30 months of age. Throughout this study, ASD will refer to individuals with a diagnosis of autism, pervasive developmental disorder not otherwise specified (PDD-NOS), or Asperger's syndrome.

Families of individuals with ASD face many challenges when trying to provide optimal health care for loved ones with this chronic neurobiological, developmental disorder. Navigation of the health care system for quality health care providers, social support services, treatment options, and educational opportunities becomes a routine requirement. Disabilities of any nature require much from family members, but caring for individuals with ASD have been found to be particularly taxing on the family system (Gupta & Singhal, 2005; Schieve et al., 2004). Prior investigative work has identified ASD symptom severity to be associated with increased stress levels in unaffected

siblings and parents (Fisman et al., 2000; Hastings et al., 2005; McHale, Sloan, & Simeonsson, 1986; Rodrigue, Geffken, & Morgan, 1993).

The functional capacity of individuals with ASD can vary, but most have a normal lifespan and may outlive their parents. Thus, siblings of those with ASD may also be future caregivers for these individuals, and this has significant social implications. To date, little is known about the resources TD adolescent siblings have that prepare them to assume this critically important role. Thus, this research builds on previous sibling research and fills a gap in the literature. An improved understanding of the resources that enhance the TD siblings' ability to adjust to living with an individual with ASD may promote healthier, life-long relationships and reduce the chronic needs of persons with ASD on society (National Institute of Health NIH, 2010; Hatfeld & Lefley, 2005).

ASD as an Indicator of Family Stress

Research over the past ten years has investigated the association of ASD severity to parent and sibling characteristics (Smith & Elder, 2010). The type of spectrum disorder and measurement contribute to differences between studies. Parental and sibling characteristics as they relate to ASD severity in previous research are summarized in the next section.

Measurement of ASD Severity

Investigators have used multiple instruments for measuring the severity of core symptoms (social reciprocity, behavior, and communication) in all types of ASD (Inglese, 2009). The instruments have different psychometric properties and ease of use. They may also be limited to specific age groups. The variety of instruments offers researchers and health providers a selection from which to choose; however, the specificity and sensitivity of the instruments vary. A reliable and valid measure of ASD

uses multi-method techniques. These include observation and assessment of the developmental level of the child, an interview with the caregiver including a detailed developmental history, and screening for associated disorders (fragile X, mental retardation). Comparison of ASD severity between studies warrants caution because of discordance between the instruments (Inglese, 2009; Saemundson, Mágnusson, Smari, and Sigurdardottir, 2003). Many factors must be considered before selecting an instrument to measure ASD severity. These include the expertise of the person evaluating, the time needed to administer the instrument, the type of data analysis, and the planned utilization of findings regarding ASD severity.

The Childhood Autism Rating Scale (CARS; Schopler, Reichler, DeVillis, & Daly, 1980) was developed prior to the DSM-IV when sensory peculiarities and stereotypical behaviors of persons with ASD were not differentiated. Despite this, the CARS is an effective measure for identifying behaviors of ASD because it includes an assessment of non-specific difficulties such as mental retardation, activity level, and language delays (Rellini et al., 2004; Saemundson et al., 2003). The instrument was originally used to diagnose ASD through observation techniques; however, parent-report has become an acceptable method by persons who have a moderate level of expertise (Schopler et al., 1980). Within the past year, a revision of the CARS, the CARS-2 (Schopler et al., 2010), has improved specificity for ASD. Following the theoretical framework of the Salutogenic model, the proposed investigation defines the stressor as ASD severity measured by the CARS-2.

Parental Stress Related to ASD Severity

The family environment is the context for the sibling relationship that is influenced by parent modeling and the individuals' interactions with one another (Weisner, 2005).

For several decades, investigations have associated parental stress levels with disability severity. Consistently, higher stress levels are found among parents of children with disabilities when compared to parents of non-disabled children (Boer & Dunn, 1992; Dyson, 1996; Lardieri et al., 2000). Furthermore, studies have shown that parents of persons with ASD have higher stress levels when compared to parents of children with other disabilities (Benson, 2006; Bishop et al., 2007; Hastings & Johnson, 2001; Schieve et al., 2007; Rao & Beidel, 2009; Tomanik, Harris, & Hawkins, 2004). These investigative findings are pertinent to sibling research because a cognitive, emotional, and behavioral response to parental stress has been found among family members (Hastings, 2002, 2003; Hastings et al., 2005).

Empirical data support elevated parental stress levels in parents of children with ASD. It remains unclear what services are warranted and under what circumstances they should be offered. Researchers investigating the behavioral symptoms of individuals with ASD and parental stress levels have used different instruments. Thus, study methodology may lead to a spurious interpretation of findings that suggest aberrant ASD behaviors increase parent stress levels (Hastings, 2002; Lecavalier et al., 2006). It is possible that a bidirectional relationship exists; however, unique family environments and cross-sectional data make it difficult to isolate predictive factors.

Herring et al. (2006) conducted one of the few longitudinal studies that examined the relationship between child behaviors and parental stress. The researchers collected data on children upon their initial ASD diagnosis and 12 months post-diagnosis. Emotional and behavior problems of 123 children (age 20-51 months) with/without PDD-NOS or communication delays were found to be significantly ($p < .01$) correlated to

behavior scores at the second data collection. In a regression analysis, there were significant differences between maternal and paternal perceptions. Mothers' stress levels ($\beta = 1.27$; $p < .01$) were significantly different from fathers' scores. In addition, differences in assessment scores of the family (mothers = 0.48, fathers' (0.36), and general health reports (mothers $\beta = 10.11$ and fathers $\beta = 8.36$) were significantly ($p < .01$) impacted by behavior scores of the child. In a final analysis, the researchers reported that the emotional and behavioral problems of the children had a greater impact on parental stress levels than the presence or absence of PDD-NOS, communication delay, or the child's gender.

Social support. Social support as a study variable has been conceptualized as the number of connections outside of the immediate family or the number of services the family utilizes for treatment of the ASD (Benson & Karlof, 2008; Fisman et al., 2000). Social support has been found to have both a positive and negative association to ASD severity and parental stress. Furthermore, social support has been found to mediate, and/or moderate the relationship between them. This discrepancy among study findings may be explained by the research design but it also suggests that social support may not be favorable under all conditions. For example, consider the following study.

A group of researchers tested social support as a moderating variable between stress and negative outcomes (Dunn, Burbine, Bowers, Tantleff-Duff, 2001). Negative outcomes of mothers ($n = 39$) and fathers ($n=19$) were operationalized as depression scores, social isolation, and spousal relationship problems. An inventory of social support was used to assess the type and amount of services parents received. An

interaction effect between social support and stressors was found; yet, there was no reduction in the amount of social isolation parents experienced. In addition, the study found social support moderated the relationship between stress and isolation such that parents with increased stress reported lower levels of isolation when they received higher levels of social support (Dunn et al., 2001).

Coping. Several investigations examined coping in families of persons with ASD, and researchers have used several theories to guide their research. The theoretical framework of Lazarus (1993) was used to ascertain what coping strategies (task-oriented, emotion-oriented, social diversion, and distraction) were predictors of parental stress in 77 caregivers of children with ASD (Lyons, Leon, Roecker-Phelps, Dunleavy, 2010). Emotion-based coping was the most frequent strategy used and its interaction with ASD severity was significant ($p = .05$). In a regression analysis, emotion-focused coping was regressed on the pessimism scale of the dependent variable (parent stress). A significant finding ($\beta = .31$, $t = 4.84$, $p = .001$) indicated that parents who used emotion-based coping were more pessimistic as the severity of the ASD increased.

Twoy, et al., (2004) examined the differences in coping scores based on family demographics of gender and ethnic background using five coping strategies identified in the resilience theoretical framework (McCubbin & Patterson, 1983). Acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal were compared to normative data. No gender differences were found on the five coping subscales. However, group results compared to normative data indicated lower mean scores in acquiring social support, seeking spiritual support, and passive appraisal. As expected, greater scores in mobilizing

resources were found in parents with children who have ASD. Cultural differences were also evident among participating subjects. While statistically greater mean scores of reframing efforts were found in Asians ($t(43) = -2.85, p = .007$), Caucasians showed higher mean scores in passive appraisal ($t(43) = 2.37, p = .022$). Furthermore, subjects who spoke English as a second language relied more on spiritual support and used significantly less passive appraisal ($t(52) = -2.87, p = .006$) as a coping strategy than the English-speaking group. These findings describe utilization of social support as a coping strategy. Ecological influences were correlated to the type of coping strategy employed by parents of individuals with ASD.

There is empirical support for an association between ASD severity and parents' mental health, social support, and coping. There are also investigations that relate parental stress levels to compromised parenting and sibling adjustment (Benson and Karlof, 2008; Fisman et al., 2000; Hastings, 2003; Macks & Reeve, 2007; Ross & Cuskelly, 2006; Verte et al., 2003). The next section reviews investigative findings related to siblings of individuals with ASD.

Siblings of Individuals with ASD

Early sibling research compared siblings of children with autism to other disability types (Gold, 1993; Mate, 1990; McHale et al., 1986; Piven et al., 1994). To date, the family composition, disability type, and sibling adjustment levels are the variables primarily examined for differentiating between sibling groups. While the majority of siblings of persons with ASD have characteristics similar to those of siblings of children with other disabilities, adjustment seems to be more difficult for siblings of individuals with ASD (Macks & Reeves, 2007; Pilowsky et al., 2004; Verte et al., 2003; Rodrigue et al., 1993).

Inconsistent research findings of sibling adjustment are explained by methodological differences and the developmental changes associated with children (Orsmond & Seltzer, 2007b). While these factors may explain differences between studies, they may also suggest that not all siblings have difficulty within their family environments. Several investigators have found data which supports adaptive characteristics within this sibling group that may not be found in siblings without a disabled family member (Benderix & Sivberg, 2007; Mascha & Boucher, 2006; McHale & Gamble, 1989; Stoneman, 2001). In this section, studies are summarized that explore ASD severity and attributes in siblings of individuals with ASD.

ASD Severity

ASD is a complex disability and a lack of understanding by TD siblings' influences their behavior and adjustment (Lobato & Kao, 2000; Ross & Cuskelly, 2006). The disruptive behavior of siblings with ASD may be regarded as usual until the TD child is mature (Bjorkland, 2005) and can comprehend the cognitive, social, or communicative impairments of the disorder (Glasberg, 2000). When the ASD disability goes unrecognized for prolonged periods, it may challenge the ability of the typically developing sibling's ability to find a sense of normalcy (Vygotsky, 1978). Avoidance or confrontational behaviors may result and lead to additional stress for the TD sibling, including difficulty establishing friendships (Bagenholm & Gilberg, 1991; Buhrmester, 1996).

In all family environments, sibling relationship stressors present challenges that erupt for multiple reasons (Kluger, 2011; Kramer & Conger, 2009), but researchers have identified additional challenges related to stress when the brother and/or sister has ASD (Orsmond & Seltzer, 2007b; Stoneman, 2001). Aggressive and unpredictable behavior

in a brother and/or sister with ASD was reported by the TD sibling as a reason for added tension within the sibling relationship (Benderix & Sivberg, 2007; Ferraioli & Harris, 2010; Mascha & Boucher, 2006). Therefore, sibling rivalry may be minimal or enhanced based on the characteristics of the TD sibling and the competencies or severity of the ASD.

One group of researchers hypothesized that TD siblings of persons with ASD would have greater expression of internalized behaviors (emotional components) based on genetic mechanisms and empirical support from prior investigative work (Pilowsky et al., 2004). The data did not support significant differences in adjustment between sibling groups. A majority (87%) of siblings in the ASD group had normal adjustment scores and when these were correlated to demographic data and ASD severity, the researchers reported that older siblings described their brother or sisters with ASD more favorably ($p < .009$) and adjustment scores were associated with ASD severity. These findings suggest that the competencies and behavior of the sibling with ASD impact adjustment in the TD sibling, and also that older siblings seem to adjust better.

Sibling Attributes

Research investigating sibling attributes includes variables of age, gender, birth order, self-competence, social competence, and characteristics of the family environment (e.g. parental traits, marital status, and parenting style). Early descriptive research compares siblings with other disabilities, and recent exploratory research examines sibling characteristics of individuals with ASD. The study findings are presented in the following discussion.

Demographics. The developmental stages of children impact adjustment levels; thus, age is a covariate in the sibling research of persons with ASD and is supported by

data in studies that have compared sibling age to adjustment (Glasberg, 2000). Gold (1993) and Rodrigue et al. (1993) found children who had an average age of nine years to have lower depression scores than older children. Contrary to this, an investigation by Verte et al. (2003) collected data from parents who reported siblings ages 6-11 had higher internalizing behavior scores (depression) than the older sibling group (ages 12-16).

In an effort to control for developmental differences, the proposed study will limit participation to adolescent siblings of individuals with ASD. Normative sibling data show that adolescents have greater conflicts than younger siblings (McHale, Updegraff, Erikson & Crouter, 2001). In addition, depressive symptoms and behaviors are more prevalent in adolescence (APA, 2008) and these are frequently associated with normative stressors (Beardslee, Gladstone, Wright, & Cooper, 2003; Tiet et al., 2001). Moshman (2005) describes the influence of modeling behaviors from peers rather than parents in adolescence. A confounding effect of age on the relationships analyzed in the proposed study will be examined.

Self Concept. In the review of the literature, few studies were found to investigate self-concept in siblings of individuals with ASD. Normative data suggest that a child's self concept is directly related to behavior scores (Achenbach, 1991a). These findings are consistent with Kaminsky & Dewey (2002). Another investigation by Verte et al., (2003) analyzed the influence of self-concept as a mediating factor of social competence in siblings of individuals with ASD. Sibling scores of persons with high functioning autism (HFA) were compared to a matched control group. Siblings of

children with HFA had higher scores on the subscales of *honesty-trustworthiness* and on *verbal self-concept* and these correlated positively to his/her self-concept scores.

Levels of depression, self-concept and behavior were evaluated by investigating group differences between siblings of persons with ASD and siblings who lived in families where the brother/sister did not have a disability (Macks & Reeves, 2007). The researchers hypothesized that there would be no difference in scores between sibling groups. However, siblings of ASD were found to have significantly higher levels of self-concept ($p < .01$), more positive views of their intellect ($p < .003$), more positive views of their behavior in general ($p < .003$), and greater anxiety levels ($p < .005$) than the control group. Because previous studies have found gender and number of siblings were risk factors associated with sibling behavior (McHale et al. 1986), a risk scale was completed for each child. Results of the analyses then predicted greater challenges in psychosocial and emotional adjustment for siblings of individuals with ASD. These data support the influence of demographic variables on the typically developing sibling's psychosocial character.

A final attribute of the typically developing sibling is the broad autism phenotype (BAP). The phenotype refers to a genetic inheritance of features that resemble one or more of the characteristics of ASD but are not severe enough to be diagnosed as ASD (Mazefsky, Williams, & Minshew, 2008; Pilowsky et al., 2004). Several research teams reported that TD siblings, especially older ones, had a greater number of language and social deficits in a group comparison of siblings in families without disability (Toth, Dawson, Meltzoff, Greenson, & Fein, 2007; Virkud, et al., 2008; Yirmiya, Gamliel, Shaked, & Sigman, 2006; Yoder, Stone, Walden, & Malesa, 2009).

A recent study by Orsmond & Seltzer (2009) investigated 57 adolescents (age 12-18) siblings who had a brother or sister with ASD and their mothers. One of the two study aims was to examine how genetic vulnerabilities (self-reported BAP factors) interacted with environment on social well-being. To answer the research question, two separate regression analyses were completed. The first one used ASD behaviors as the stressor and regressed sibling depression and gender. Both were found to be significant predictors ($p < .05$). A trend ($p < .10$) was found when sibling BAP and behavior problems were used as interaction terms. In the second regression analyses, a sibling life event was operationalized as the stressor and outcome variable. In siblings with high BAP scores, depression ($B = .39$; $p = .05$) and anxiety scores ($B = .36$; $p = .05$) were significantly predicted. It is not clear if the expression of altered communication and social deficits in unaffected siblings is related to the environment or genetics. Thus, investigators must carefully consider a screening measure or exclusion criteria for cognitive or learning differences when enrolling unaffected siblings of individuals with disability (Seltzer, Abbeduto, Krauss, Greenberg & Swe, 2004).

Sibling adaptation & adjustment. Sibling adaptation is a major concept in the literature and can be defined as the development of physical and behavioral characteristics that allow siblings to thrive in their environments (Wiley & Allen, 2009). The literature review on parental characteristics and sibling attributes offers explanations for poor adjustment in typically developing siblings of individuals with ASD (Lewis et al., 2006; Mugno et al., 2007).

Hastings' (2003) cross-sectional exploratory study compared sibling adjustment scores using the Strengths and Difficulty Questionnaire (SDQ; Goodman, 1997) across

two groups of typically developing siblings who had a brother/sister with a disability (ASD and DS) and a normative sample. Maternal stress levels were also correlated to the behaviors of the child with ASD. Typically developing siblings of children with either disability type had greater overall adjustment problems on the SDQ, and lower levels of prosocial (interaction) behavior than the normative sibling group. In the hierarchical regression analyses, maternal stress and behavior of the disabled were not predictive of adjustment, yet demographic variables (SES, family size, education levels) explained 35% of the variance. Sibling variables (age, gender, and birth order) accounted for a significant proportion of the variance (55%). Consistent with Kaminsky & Dewey (2001), females were found to adjust more easily.

Ross & Cuskelly (2006) found that adjustment was associated with coping skills and knowledge of ASD in a group of typically developing sibling individuals with ASD ($N = 25$). Sibling participants rated recent interactions with their affected brother or sister with ASD and the coping skills they initiated. The responses were then classified into five categories. The investigation revealed that 52% of the siblings of individuals with ASD classified an interaction as *aggressive*; 20% described it as a *social problem*; 16% as *syndrome specific*; 4% as *concern* for their sibling and 8% as *unclassified*. Eleven children reported two incidents of aggressiveness on the Child Behavior Checklist (CBCL; Achenbach, 1991) and for them sadness was highly correlated and significant ($p < .001$), while nervousness and anger were moderately correlated but insignificant ($p > .001$). Twenty-one children (84%) reported at least one aggressive incident. The researchers further analyzed coping strategies and discovered that the most common strategy was wishful thinking, followed by social withdrawal, distraction, problem

solving, social support, resignation, cognitive restructuring, blaming others, and self-criticism. Although the investigators did not find that coping and knowledge of ASD contributed to sibling adjustment scores (measured by the mother), there were differences in adjustment scores in siblings of individuals with ASD. Normative data comparisons showed TD sibling scores were 40% lower in adjustment, although the mean scores on behavior comparisons were similar (Ross & Cuskelly, 2006).

The findings of sibling adaptation levels and sibling behaviors of persons with ASD are not yet fully understood. To provide greater understanding, larger study samples comparing siblings on individual factors (demographics, behaviors, and adjustment) or longitudinal data are needed. Antonovsky & Sagy's (1986) seminal work suggests that resources and psychosocial stress have a direct relationship.

Summary

The behavior and severity of the ASD disability, parental characteristics, family environment, and characteristics of the TD sibling influence adaptive responses to the ASD. Previous research has identified higher adjustment scores in older female siblings and family environments with higher SES and education levels (Hastings, 2003; Kaminsky & Dewey, 2001). Direct measures of the TD siblings' characteristics may prove to be more accurate than parents' report (Verte et al., 2003). Research within the past ten years on TD siblings has also identified a phenotype expression of mild forms of the ASD disability that requires prior screening before investigation (Pilowsky et al., 2004; Mazefsky et al., 2008; Toth et al., 2007; Yirmiya et al., 2006).

In order to manage tension created by stress, individuals utilize internal and external resources (Antonovsky, 1987; Folkman, 2000; Lazarus, 1993; Moos, 1984). The proposed study will operationalize resources through examination of the TD

siblings' psychological well being, coping strategies, and relationship networks. A brief overview of the literature describing each of these factors is summarized in the following section.

Sibling Resources

There is adequate empirical data to support the theory that the needs of a child with ASD may add a significant stressor to the family environment. Siblings of individuals with ASD are socialized into a family environment and the type and utilization of resources they attain may be heavily influenced by interacting variables within the family (Compas, Connors-Smith, Saltzman, Thomsen, & Wadsworth, 2001; Singh et al., 2007). For example, parents adjust to the needs of their child with disability and may alter the type of parental guidance, discipline, and attention given to TD siblings (Powers, 2004). Biological, psychological, sociological and cultural factors determine the resources available to individuals (Weisner, 2005), thus influencing their life orientations (Antonovsky, 1987).

Orsmond et al. (2009) compared the relationship between the TD *adolescent* sibling and the TD *adult* siblings of individuals with ASD and found adult sibling relationships with their brother/sister with ASD to be influenced by their early environment and resources. These findings are consistent with other investigations of the TD siblings in early childhood. Researchers have found that factors contributing to the interactive nature of sibling relationships were dependent on the TD sibling's coping styles, family resources and sibling perceptions of the ASD severity (Yoder, et al., 2009; Knott, Lewis & Williams, 2007; Yirmiya et al., 2006).

A first step for promoting the health and adjustment of TD siblings of individuals with ASD is to identify what resources and environments contribute to positive

outcomes. If specific resources can be linked to favorable sibling disposition, vulnerable environments may be identified. Furthermore, intervention studies can be completed for an evaluation of their impact for improving interactions within sibling dyads (Knott et al., 2007; Kramer & Conger, 2009). This is vital for the unaffected sibling who may be a future caregiver for his/her brother/sister with ASD (Blacher & Begum, 2009; Feiges & Weiss, 2004; NIH, 2009). In this section, sibling research studies related to support, relationships, coping, and psychological well being are presented.

Social Support

In the literature review of adolescence, social support has been measured directly and indirectly with adjustment as the outcome measure. Social networks, psychosocial assets, and appraisal of the support are common definitions of the social support construct. The variety of operational definitions measured across studies of child and adolescent health, including investigations reviewed for siblings of individuals with autism, makes it difficult to assess social support (Meaden, Stoner & Angell, 2010).

An accurate assessment of sibling social support must consider the siblings' developmental level and psychological well being (Iervolini et al., 2002). Gupta & Singhal (2005) report that children < 12 years old recognized social support as the amount of caregiving received. In contrast, older adolescence (> age 12) defined social support as peer relationships or experiences outside the home. Consistent with this finding, a longitudinal investigation of adolescent girls (N = 456) found peer support ($r = 4.36$) was greater than parental support ($r = 3.88$) for all three time points (Stice, et al., 2004). This data suggests adolescent peer relationships impact social support. The research team also discovered that the adolescents who reported low levels of parental and peer support had significant levels ($p < .02$) of depressive symptoms and this

finding was greater for females. Lazarus & Folkman's (1984) theory posits social support and depression have reciprocal relationships and this finding has been supported in investigations of adolescents (Huang & Guo, 2009).

The construct of social support in ASD research has been defined as a network of relationships and includes an appraisal of the quality of social interaction. Kaminsky & Dewey (2002) investigated whether TD siblings (N = 90) aged 11-12 of children with ASD had differences in psychosocial adjustment and loneliness when compared to siblings of children with Down's syndrome (DS) and siblings of children without disabilities. The researchers found that self-reported support from friends was higher among siblings across all groups, but siblings of individuals with DS or ASD reported higher levels of support from family members and teachers than the control group. Siblings of individuals with ASD and DS self-reported lower loneliness scores when these were compared to peers of the same age. No gender or interaction effects were discovered, nor was a significant difference found in scores between siblings of those with ASD and siblings of individuals with DS. The findings from this study suggest that TD siblings of individuals with ASD and DS have an adequate network of social support.

Sibling Relationships

The sibling relationship quality can be argued as an indicator of social support because of its significance as a psychosocial asset for all siblings within the family environment (Brody, 1998; Kim et al., 2007). Thus, it has been used as a predictor of adjustment and an outcome variable in the research on siblings of persons with ASD (Kaminsky & Dewey, 2001; Orsmond & Seltzer, 2009; Rivers & Stoneman, 2003).

Kaminsky & Dewey (2001) examined the effects of dominance, affection, companionship, intimacy, admiration, and competitiveness in sibling relationships

among three groups (N =90). The severity of autism, SES, family size, and maternal education were compared among siblings. Siblings of persons with ASD, DS and without disability were age- and gender-matched. Although no significant differences were found among groups on familial demographic data, there were differences in the relationship scores. Siblings of children with ASD and DS reported significantly ($p < .01$) greater admiration for their brother/sister than siblings of children without disability and significantly ($p < .001$) less quarreling and competitive behaviors. *Post hoc* comparisons between groups showed siblings of children with ASD had less social interaction compared to siblings in the control group. This was not true for siblings of children with DS who had similar levels of social interaction as siblings of children without a disability.

As part of a longitudinal study, Orsmond et al., (2009) compared TD adolescent ($n = 57$) and adult ($n = 142$) sibling relationships by measuring their levels of involvement and affection. The aim of the study was to explore sibling relationship characteristics and examine predictors of psychological well being, coping and social support. A major finding from the study was that adolescents engaged in significantly ($p < .001$) more shared activities with their siblings than adult participants did; however, measures of positive affection in the sibling relationships were not statistically significant between age groups. Consistent with previous research, female siblings participated in more shared activities during adolescence with their disabled siblings but there were no gender differences in the adult group (McHale & Gamble, 1986, Orsmond et al., 2009). In addition, social support from family members and friends was found to be greater in adolescents ($p < .001$) than in the adult group. The researchers also discovered that adult siblings who reported a positive affect in their sibling relationship also reported

higher levels of parental support. Depression scores as a measure of psychological well being were examined between sibling groups and no differences were found. When comparisons among *only siblings*, *closest siblings in age of multiple siblings*, and *other* were made, depressive symptoms were found to be a significant predictor of relationship quality for *siblings closest in age* for both the adolescent and adult groups (Orsmond et al., 2009).

Rivers & Stoneman (2003) found that family levels of adjustment (indicated by social support and marital status) correlated with the quality of the sibling relationship. The authors hypothesized that marital stress would have an unfavorable influence on the sibling relationship but would be mediated by increased levels of social support. The investigation found that marital stress and social support interacted to predict the quality of the sibling relationship. Interestingly, the benefits of social support were found only in families that reported positive sibling relationships. Siblings in unfavorable relationships and environments of marital stress remained there despite social support resources. It is not clear for these families if social support added to the stress within the environment, or if a troubled sibling relationship was the reason the family was utilizing social services. Regardless, data indicate different patterns of behavior are exhibited in favorable relationships than in unfavorable relationships (Rivers & Stoneman, 2003). Similar to other study findings (Macks & Reeve , 2007; Orsmond et al., 2009), the data of sibling birth order and age span between siblings suggested older siblings had better relationships with the child with ASD and parents' scores of sibling relationships were lower than siblings' self-reported scores.

In order to examine the sibling relationship in concordance with other realms of social support, the Network of Relationship Inventory-Social Provision Version (NRI-SPV; Furman & Buhrmester, 2009) was used. This revised instrument is similar to the Sibling Relationship Questionnaire (Buhrmester & Furman, 1990), which has been used in prior research in siblings of individuals with ASD (Fisman et al., 2000; Floyd, Purcell, Richardson, & Kupersmidt, 2009; Kaminsky & Dewey, 2001). The NRI-SPV provides a matrix of relationships that can be used to compare and contrast subscales of support, power, and conflict in relationships with the subjects' sibling with ASD, parent, and friend.

Coping

The concept of coping denotes a person's active role in dealing with stressors in the context of any given life situation (Antonovsky, 1979; Lazarus 1993; Moos, 1984). The majority of research on children and adolescents has focused on differences between individuals within a population in order to examine what types of coping contribute to successful adjustment (Blount, et al., 2008; Skinner & Zimmer-Gembeck, 2007). Consistent with this approach, studies investigating coping strategies of siblings of individuals with ASD have examined coping in relationship to individual characteristics (age, gender, birth order), parental influences (mental health, stress levels, marriage), and psychosocial variables (anxiety, behaviors, depression, self-concept). Although empirical support indicates that the construct of coping is of vital importance when examining the effects of stress, it is unclear what type of coping strategies produce optimal health outcomes in TD siblings of individuals with ASD (Dellve, Cernerud, Lillemor, & Hallberg, 2000; Orsmond & Seltzer, 2007b; Ross & Cuskelly, 2006).

Orsmond & Seltzer (2009b) examined predictors of sibling relationship quality in adult and adolescent siblings of individuals with DS and ASD (N = 301). Three instruments measured the TD sibling resources and appraisals. First, an appraisal tool (designed for the study) measured the impact of the disability on eight areas of the siblings' life. Next, siblings completed a coping inventory that measured four subscales of problem-focused coping (active coping, planning, suppression of competing activities, and positive interpretation/growth) and four subscales of emotion-focused coping (denial, focus on and venting of emotions, behavioral disengagement, and mental disengagement). In addition, a measure of pessimism was included. No significant differences in levels of coping were found between adolescent and adult sibling groups; however, siblings of individuals with ASD reported greater levels of pessimism than siblings of individuals with DS.

Dellve et al. (2000) conducted a qualitative investigation aimed at understanding the coping mechanisms of siblings of children with deficits in attention, motor control, and perception (DAMP) and siblings of children with Asperger's syndrome. Using inductive analysis, the researchers found that the coping process could be conceptualized into four categories: gaining understanding, gaining independence, following a bonding responsibility, and balancing. The researchers found that differences in coping processes were related to the siblings' expression of *requirements* vs. *concerns* for their brother or sister with a disability.

Conceptualized categories of coping are defined in a broad sense. Common responses to stressors include the mechanisms used to manage the stressor for a specific situation (cognition, perception, behavior). Researchers are also interested in

the long-term effects of the individuals' coping strategies. Unfortunately, more research is needed to define clearly the subtypes of coping and identify which are most effective in childhood and adolescence (Compas et al., 2001; Skinner, Edge, Altman, and Sherwood, 2003).

The Adolescent Coping Orientation for Problem Experiences (A-COPE; Patterson & McCubbin, 1987) was developed to address the unique stressors of adolescence, including identity formation, assuming autonomy from parents, and conforming to peer and social demands. The measure has been used in healthy male and female adolescents (N = 361) as a tool to evaluate the most frequently used coping strategy in difficult situations (Chapman & Mullis, 2000). The investigators used multiple factor analyses of the 12 subscales to differentiate three types of coping strategies (problem-focused, cognitive-focused, and emotion-focused). Emotion-focused coping was the most common strategy used by both groups of 7th through 12th grade students. These findings are concerning because emotion-focused coping strategies are not aimed at the core problem and have been found to be associated with psychological maladjustment (Moos, 1984).

Psychological Well Being

Psychological well being is defined as an optimal state of health or adjustment in the proposed study. The construct of *well being* has been operationalized in the majority of investigations in TD siblings of individuals with ASD by scores on behavioral measures (Meaden et al., 2010). In addition to behavior scores, psychological well being in siblings of individuals with ASD has also been defined as self-competence and self-concept (Macks & Reeve, 2007; Verte et al., 2003). Quality of life and stress measures have been used in family adjustment and adaptation research (FAAR)

frameworks, but thus far parents have completed these measures because instruments suitable for children and adolescents are not available.

A plethora of research in children has examined the relationships among stress, family function, and psychological events. Research investigations have revealed that these concepts are directly related. As the number of adverse life events increases, reported levels of depression and disharmony within the family increase: these findings are particularly salient in adolescent populations (Pike & Eley, 2009; Sholte et al., 2007; Tiet et al., 2001).

Two global patterns of behavior are evaluated by the CBCL (Achenbach, 1991) in many studies to operationalize adjustment and psychosocial well being in TD siblings of individuals with ASD. Internalizing (shy, anxious) and externalizing (aggressive, acting-out) behaviors of unaffected siblings has been associated with the stress of the family environment and the severity of maladaptive behaviors in the brother or sister with ASD (Hastings, 2003; Ross & Cuskelly, 2006; Verte et al., 2003). These behaviors have been associated with marital satisfaction and birth order but findings are not consistent. Rodrigue (1993) reported that older TD siblings' parents reported higher scores on the two global patterns of behavior (internalizing /externalizing) and suggested that siblings may find it difficult to adapt when there are abrupt changes in family life. In contrast, Hastings (2003) found that while siblings of individuals with ASD had lower adjustment scores than a control group, both genders had better adjustment scores if they were older than the affected brother/sister.

Typically developing (TD) siblings of individuals with ASD describe aggressive behaviors of their brother or sister with ASD as a factor that contributes to difficult

relationships and increased stress within the family environment (Benderix & Sivberg, 2007; Mascha & Boucher, 2006). Aggression in one sibling has also been linked to higher levels of externalizing behaviors in other siblings (Natsuaki, Ge, Reiss, & Neiderhiser, 2009). For example, a research design included 390 sibling pairs that were monozygotic and dizygotic twins, full siblings, half siblings and unrelated siblings. These groups were separated and evaluated over two waves of data collection. Aggression in one sibling was associated with externalizing behaviors in the other sibling at both time intervals despite controlling for pre-existing externalizing behaviors and punitive parenting across sibling groups. These findings suggest that clinicians should assess each sibling's behavior within the family when examining the psychological well being of siblings.

Summary

Further research relating sibling resources is necessary based on the review of the literature for siblings of individuals with ASD. Within this population, there is empirical data to support inconsistent levels of adjustment despite twenty years of investigation. Social support, coping, and psychological well being are constructs that have self-reporting instruments with adequate psychometric properties for examining their impact on the TD sibling. The association of sibling resources to ASD severity and life orientation or sense of coherence (SOC) will be examined to further characterize the adolescent sibling. In the final section of the literature review, a summary is provided of investigations that have used the SOC instrument in adolescent populations.

Life Orientation and Coping

Life orientation is defined as a person's disposition toward his or her life situation and was operationalized by Antonovsky (1979) in the *sense of coherence* (SOC)

instrument. A person's level of SOC determines his/her ability to regain composure (cope) under tension (by-product of stressor). In other words, a person reporting high levels of coherence will remain healthy in the face of stressful situations. The SOC is a stable indicator of coping influenced by resources that can vary within an individual by approximately 6% from the mean over time and still be considered unchanged (Antonovsky, 1987; Honiken et al., 2009; Kuppelomaki & Utriainen, 2003).

The Salutogenesis Model (Antonovsky, 1987) posits that individuals have resources that influence their tension management and impact their health. According to Antonovsky (1987), the SOC is a "global orientation" (p. 19) meaning that it is stable between stressors and remains stable once it is established. Life orientation is also a process. Thus, the SOC is dynamic between populations and during stages of development (Kuppelomaki & Utriainen, 2003; Antonovsky & Sagy, 1986). The SOC in early adolescence is characterized by unpredictability and young teens are expected to have lower levels of SOC than teens in the later years (Antonovsky, 1996; Antonovsky & Sagy, 1986). By early adulthood (age 30), Antonovsky (1987) claims a person will have established a rational and consistent way of looking at the world.

The SOC concept describes the outlook of the TD adolescent sibling and it is used to test the Salutogenesis Model. The relationship of the SOC to the symptom severity of the ASD and the siblings' resources is examined. The remainder of the literature review identifies previous research that has correlated the SOC concept to stress and resources.

SOC and Stress

A longitudinal study (N= 1435) examined the stability of SOC levels over a five-year period in adults aged 25-74 years old and correlated SOC scores to health and

social support measures (Nilsson et al., 2006). Participants' SOC scores that were significantly greater ($p < .01$) at the point of initial data collection remained higher than the mean scores at the second data collection. The investigators reported a significant ($p < .001$) drop in the SOC scores over time from subjects who were older, had lower SES, and had chronic health problems.

Myrin & Lagerstöm (2006) conducted a cross-sectional study and administered SOC and behavioral health instruments to 14-15 year-old eighth-grade students (N= 383) from six public schools. The researchers examined the effects of SES and gender on each variable. No differences in coherence were found between the two socioeconomic groups; however boys (49%) had significantly higher SOC scores ($t = 4.50$; $p < .001$) than girls. Furthermore, a greater number of problematic health behaviors (eating disorders, drugs, and activity levels) were reported by girls of higher socioeconomic status and were significantly related to lower SOC levels.

A final study looked at the moderating effects of SOC on stress and health. Nielsen & Hansson (2007) examined self-reported illness and self-reported symptoms as an outcome measure. In a randomized sample of urban students (N=3458), stress and SOC were measured in adolescents. Participants indicated whether they had been exposed (yes/no) to divorce, death or disease of family member, conflict, or *other* stressful events. The adolescents were also queried on nine confounding variables: parental support, academic achievement, communication ability with parents and peers, well being at school, breakfast, smoking, and pubertal development. In the final analyses, two groups (none and > 1) were formed. Logistic regression of the two health outcomes (*self-reported illness/self-reported symptoms*) and gender was performed.

First order associations were included in two models. Both models included an interaction term of stress and SOC and the second model included the confounding variables. The prevalence of poor health outcomes on both measures was higher in adolescents who reported stress and low coherence levels. Girls had a greater number of adverse health outcomes than boys and these were significantly ($p = .01$) associated in both genders to levels of SOC. When controlling for confounds, the experience of severe stress was associated with poor health outcomes (*self-reported illness*) but not for the SOC scores. The findings suggest that the SOC is stable in adolescents who have high stress levels and are consistent with the Salutogenic model of coping.

SOC and Resources

Honiken et al., (2009) published a longitudinal investigation that aimed to examine the association between SOC scores in adolescence to psychosocial indicators on subscales of the CBCL and YSR. In addition, the researchers conducted a regression analysis on the subscales and problem syndromes of the instruments to examine whether the presence of certain behaviors as indicated by these instruments predicted SOC levels (Honiken et al., 2009). Baseline data (CBCL, YSR, and SOC instruments) were collected from parents in various pediatricians' offices when their children were 3 years old ($N = 1086$) and subsequent data collections were undertaken when the participants reached age 12, 15, and 18 ($N = 840$). Findings revealed that at both the third and fourth data collection (age 15 and 18), boys SOC levels were significantly greater than girls (65.4 vs 60.8; $p < .0001$; and 65.4 vs. 61.7; $p < .0001$), but remained stable across groups over time. The predictors (CBCL and YSR) at age 18 showed a significant gender interaction on three subscales with males scoring higher than females: externalizing problems ($p = .02$), attention problems ($p = .02$), and delinquent

behavior ($p = .02$). Furthermore, there was an inverse relationship on CBCL total scores and externalizing problem scores to SOC scores ($p < .0001$). Two symptom subscales of the externalizing behaviors (aggressive and destructive behaviors) also predicted SOC scores with maladaptive scores increasing over time. Furthermore, the researchers reported that parents' ratings were significantly different ($p < .05$) than adolescent scores using the YSR. The overall findings of the study suggest that early childhood behaviors have an effect on later behavior and SOC scores.

Summary

Siblings of individuals with ASD are an understudied group that has been found to be resilient in nature and to have adjustment difficulties. There are likely characteristics of the sibling groups that use different resources (coping, social support, and psychological well being) to thrive in the family environment. Life orientation is a construct at the center of the Salutogenic Model and is used as the dependent variable in this study through the Sense of Coherence instrument (Figure 1-1).

In the next chapter, the associations of ASD severity, TD sibling resources, and sibling SOC scores are examined through a correlation framework. Additional analyses test the model and include significant relationships in hierarchical regression models to examine each resource as a mediating and moderating variable (Baron & Kenny (1986).

CHAPTER 3 METHODS

The majority of psychosocial studies found in the literature review compared siblings of individuals with an autism spectrum disorder (ASD) to siblings of typically developing (TD) youth or individuals with other disabilities. There is a paucity of research examining the associations of psychological well being, coping strategies, and relationship networks to health/wellness within a group of adolescent siblings of individuals with ASD. Thus, it remains unclear which sibling resources may be effective to reduce tension and manage stress related to having a brother/sister with ASD. Therefore, it was the purpose of this study was to describe characteristics of adolescent, TD siblings of individuals with an ASD and examine resources that influence their coherence levels using the theoretical framework of Salutogenesis (Antonovsky, 1987) to guide the research.

Research Design

The study employs a descriptive, exploratory research design to assess the characteristics and behaviors of adolescent siblings of individuals with ASD and to examine the conceptual relationships of the Salutogenesis model (Antonovsky, 1987). Although causal relationships cannot be evaluated using this methodology, the investigation provides beneficial information about these relationships and future interventions for experimental studies.

Sample

A purposive, convenience sample was comprised of TD adolescent siblings (aged 11-18 years) of brothers/sisters diagnosed with autism, Asperger's syndrome, or Pervasive Developmental Disorder-Non Specified (PDD-NOS; herein referred to as

ASD). At the end of the recruitment period, 160 families were enrolled and 99 families returned the research packet for a 62% response rate. The study sample (N=96) was reduced because three families did not meet inclusion criteria (Appendix A).

Demographic information was completed by parents and contained information about the family environment, TD adolescent sibling, and their child with ASD. Individuals with ASD were between 2-22 years of age (mean 12.04, SD 4.5) and their diagnoses were confirmed using the parent completed Child Autism Rating Scale-2nd Edition (CARS2; Schopler et al., 2010).

Power. In order to present meaningful results a 5% risk of committing a Type I error and a 20% risk of committing a Type II error was accepted. The Bonferonni procedure ($.05/k$ where $k = 12$) was used in answering the first research question to reduce the risk of Type I error when reporting multiple significance (Warner, 2005). The α was reduced to .004 in the analyses of sibling gender and birth rank to all the major variables. To test the theoretical model, a sample size (N=96) was adequate for six predictors and a large effect size ($R^2 = .58$) was established (Cohen, 1988). Further increase of statistical power was obtained through a homogenous sample (Table 3-1).

Recruitment. The primary recruitment strategy for siblings was through Internet-based websites of national and local autism provider groups. Study notifications were posted to chapters of the *Autism Society of America*. The Primary Investigator (PI) volunteered as the Scientific Ambassador (community liaison) for *Autism Speaks* and advertisement for the study was provided on their national website. In addition, local providers of healthcare or social services to families with members on the autism spectrum were contacted and asked to assist with recruitment. Some providers made

contact with their constituents; others agreed to post IRB approved flyers in their waiting rooms. Finally, two *Centers for Autism and Related Disorders (CARD)* and the *International Autism Network (IAN)* recruited study participants. Approximately 25% of the sample originated from Florida and 27 states were represented in the final sample. Despite this, participants were an overall homogenous group (see Table 3-1).

Instrumentation

Data were collected using instruments that required participants to answer questions with pen/pencil (Appendix B). Because the study was mail-based, parents were encouraged to contact the PI by telephone or email as necessary and to freely answer any questions their child had while completing the self-administered questionnaires. Parents completed a demographic sheet and the CARS-2 (Schopler et al., 2010). The self-reporting instruments completed by the adolescent siblings included: (a) the Youth Self-Report (YSR; Achenbach, 2001), (b) Adolescent Coping Orientation for Problem Experiences (A-COPE; Patterson & McCubbin, 1987), (c) Network Relationship Inventory-Social Provision Version (NRI-SPV; Furman & Buhrmester, 1994), and (d) the Sense of Coherence (SOC; Antonovsky, 1987).

Demographic information. A demographic form was developed to obtain information about the family environment and included listing current residents within the family household by age and gender (names omitted). Separate sections for mothers and fathers elicited information about each parent's educational status, employment, and amount of additional time they spent care-giving their child with ASD. The person completing the form identified ethnicity, diagnosis of the ASD, and whether professional treatment for the ASD was currently received. The reported length of time to complete the demographic form was five minutes.

Child Autism Rating Scale. The Child Autism Rating Scale-2nd Edition (CARS-2; Schopler et al., 2010) was used to measure ASD severity. The second edition is revised and includes two versions – a standard (ST) and high functioning (HF). Parents were asked the diagnoses of the family member and if they reported a diagnosis of “Asperger’s syndrome” a CARS2-HF was mailed to them. Some parents identified their child as having autism but indicated Asperger’s syndrome on the demographic questionnaire. Thus, CARS2-ST versions were completed on individuals with a higher functioning ASD. Both versions of the CARS-2 instruments distinguish between mild, moderate, and severe autism but raw scores rather than severity levels were used in the analysis because two versions of the instrument were used to describe one sample.

The CARS-2 can be completed in 5-10 minutes and requires minimal training for quality administration (Schopler et al., 2010). On the phone or via email, parents were advised that they would complete the CARS-2 instrument and that professionals used the measure for differentiating the ASD diagnoses from other disability types. Parents were reassured of their capability in completing the questionnaire and were told: 1) to read all the answers for each question before selecting the answer that *best* describes their child, 2) to avoid *over* or *under*-estimating their child’s capability, and 3) the ASD severity score was a major study variable. Each instrument provided an area to write a description for each question and parents were instructed to use it to clarify their answers.

The CARS-2 uses a Likert- scale for 15 items. Behaviors are rated in comparison to an unaffected individual of similar age to their child with ASD. The score *1* denotes a *normal* behavior and a score of *4* depicts a *severely abnormal* behavior. The scores are

summed across four subscales to obtain a total raw score. T-scores can be obtained for percentile ranks (Schopler et al., 2010). The CARS is widely used and adequately differentiates levels of ASD severity. Total scores > 30 are strongly suggestive of ASD. Scores > 37 are considered moderate to severe (Magyar & Pandolfi, 2007).

Reliability and validity have been established for the CARS-2 standard (ST) and the CARS-2 high functioning (HF). Chronbach's alpha coefficients range from .43 to .81 with a median value of .69 for CARS2-ST and .53 to .88 with a median value of .79 for the CARS2-HF. In an examination of the test-retest reliability of the instrument, Schopler et al. (1980) found an alpha of .88 for the total score, although reliability was reduced in 10 of 15 adolescents assessed twice over a four-year interval. Another study found the instrument to have adequate inter-rater agreement with a Pearson correlation coefficient of .73 (Schopler et al., 2010). Magyar & Pandolfi (2007) found that internal consistency coefficients fell below .80 on all four factors: social-communication ($\alpha = .78$), social interaction ($\alpha = .61$), stereotypes and sensory abnormalities ($\alpha = .54$), and emotional regulation ($\alpha = .59$). The CARS has also been examined for content and convergent validity with the DSM-IV (Rellini et al., 2004) and the ADI-R (Saemundsen et al., 2003). Convergence is reported as 100% between the CARS and DSM-IV criteria and 66.7% (Cohen's kappa = .40) between the ADI-R and the CARS. The CARS-2 (Schopler et al., 2010) is a revised edition and takes into account the intellectual functioning by administration of a Standard and High Functioning version. It has sensitivity levels of .79 and specificity is .58 with a false positive rate of 27% and a false negative rate of 36%. In this study, Chronbach's alpha of the CARS-2 for the combined version was .89.

Youth Self Report. The Youth Self Report (YSR; Achenbach, 2001) is a measure of social competencies and behavior problems in youth. This instrument includes many of the same items as the CBCL (Achenbach, 1991) for ages 4-18; and the teacher report form (TRF; Achenbach, 1991). It was developed to obtain 11-18 year olds' reports of their own competencies and problems in a standardized format. This measure is one component in multiple assessments necessary to accurately evaluate competencies and problems in adolescents (Achenbach, 1991).

The YSR is designed for a fifth grade reading level and was completed independently by 11-18 year-old TD siblings. The YSR is comprised of 112 self-report items answered by circling 0 if item is *not true*, 1 if the item is *somewhat true* or *sometimes true*, and 2 if the item is *very true* or *often true*. On several items, the youth is asked to describe the problem in question. A score for every problem item is provided in addition to sum scores (raw) scores. *T* scores for the syndrome scales – *internalizing* & *externalizing*, and *total problem* can be reported when comparing scores from different study samples.

Reliability and validity have been established for the YSR (Achenbach, 1991a; Achenbach, Dumenci & Rescorla, 2002; Ivanova et al., 2007). One week test re-test reliability for the *problem* scales was $r = .68$ for 11-14-year-olds and $r = .83$ for 15-18-year-olds. On the *total* problem score, the r was $.70$ for 11-14-year-olds and $.91$ for 15-18-year-olds. Over a 7-month interval, the r was $.49$ for *problem* scales in a general population of 11-14-year-olds and $.56$ for *total* problems. In a sample of 15-17 year-olds, 6-month stability was $r = .69$ for the *total* problem scale (Achenbach, 1991a).

Internal consistency has also been established for each problem scale and the total problems score: externalizing scale ($\alpha = .89$), internalizing (.89) and total problem scores (.95). In this study, the total problem scale was used to measure the amount and type of difficulty (resource deficit) that the sibling may be experiencing. It was derived from the following subscales: *anxious/depressed*; *withdrawn/depressed*; *somatic complaints*; *social problems*; *thought problems*; *attention problems*; *rule-breaking behavior*; *aggressive behavior*; and *other problems*. Higher scores indicated a greater number of behavior problems. Cronbach's α was .95 on the *total problem* scale and ranged from .78 to .87 on the nine subscales.

The YSR has also shown good content and convergent validity. Its design was based on the CBCL, and all but the *asthma* and *allergy* problem items were significantly correlated; thus, they were eliminated from both measures (Achenbach, 1991). Content validity for the YSR was supported in a sample of matched referred and non-referred youths through significant discrimination of instrument items. Criterion validity was supported in the analyses after demographic factors were controlled (Achenbach, 1991). The YSR is a well-established clinical tool for the measurement of behavior and adjustment in youth. In addition, the CBCL is one of the most widely used measures of child behaviors and is cited in a majority of sibling studies in the ASD research literature (Orsmond & Seltzer, 2007; Stoneman, 2001). Raw scores rather than *T* scores are recommended for use in statistical analyses and normative comparisons. This tool has multiple applications including epidemiology, screening for potential diagnoses, the measurement of intervention outcomes, and the identification of problematic behaviors related to medical conditions (Ivanova et al., 2007).

Network of Relationship Inventory-Social Provisions Version. The NRI-SPV (Furman & Buhrmester, 1985) is a standardized measure used to identify roles that network members play in meeting a variety of social needs in children, adolescents, and adults. The 38-item questionnaire is appropriate for individuals 11 years and older. Participating siblings were asked to identify the parent as “biologic or adopted mother;” “step mother or father’s significant other;” “biologic or adopted father” or “other.” In addition, they were asked to identify one friend of the same sex and then estimate the length of friendship in years and months. Finally, they answered the questions in regard to their brother or sister with ASD. The length of the sibling relationship was calculated by first taking absolute values of the difference in sibling age and then adding this value to the younger TD sibling’s age or subtracting the age difference if siblings were older.

The adolescent sibling used the NRI-SPV to rate how often the quality occurred in each relationship (one *parent*, *sibling* with ASD, and same-sex *friend*). For example, “How much do you protect and look out for this person?” They rated their answers using a Likert-scale ranging from 1-5; *little or none* (1), *very much*, (2) *somewhat*, (3) *very much*, (4) *extremely much*, or (5) *the most*. Higher scores indicated a greater amount of perceived support. Seven of the subscales (*affection*, *reliable alliance*, *enhancement of worth*, *intimacy*, *instrumental help*, *companionship*, and *nurturance of other*) were used to provide a scale scores. In this study support scores were kept separate for parent, friend and sibling in the bivariate and multivariate analyses.

Reliability and validity have been established for the subscales of this instrument, and for identifying similarities and differences among the parents, friends, and siblings in the social networks of children and adolescents (Furman & Buhrmester, 2007; Noack

& Buhl, 2004). Internal consistency has been established for each subscale and for each relationship (alpha ranges .59 - .95). Test-re-test reliability data was examined in 200 adolescents (100 female) over a one-year interval. Both the scale identifying support features and the scale identifying negative interactions were significantly correlated across time points (ranging from .49 to .70) and were stable in relationships with parents and in relationships with friends. There was a significant effect related to relationship type [$F(5, 870) = 82.52, p < .05$], with mean subscale and scale scores varying across parents (mothers/fathers were identical), siblings, and friends (Furman & Buhrmester, 1985).

Averaging the three items that make up each subscale derives scale (factor) scores on the NRI-SPV and this was done because more than two items were answered. In this study, the social support scale score for parent, friend, and sibling were entered into the model and Cronbach's alpha ranged from .84 -.86.

Adolescent Coping Orientation for Problem Experiences. Adolescent siblings completed the A-COPE (Patterson & McCubbin, 1987) because the instrument examines the strategies adolescents engage in when managing tension or taking action to resolve a problem. This 54-item instrument is designed for persons age 11 and older. Each item is prefaced with the phrase, "When feeling tense or facing a problem or difficulty how often do you...?" Adolescents respond to each item on a 5-point Likert scale (*1 = never; 2 = hardly, 3 = sometimes; 4 = often, and 5 = most of the time*).

Test-retest reliability for the instrument ($r = .83$) is adequate (McCubbin & Patterson, 1987). The A-COPE has been used to evaluate coping behaviors in healthy populations, in psychiatric populations (Recklitis & Noam, 1999), in populations with

chronic health conditions, and cross-culturally. Thus, it is considered a well-established instrument that reliably measures coping behaviors in adolescents from a variety of backgrounds and with a variety of potential life stressors (Blount et al., 2008). Reliability and validity data have been reported for the A-COPE (Blount et al., 2008; Copeland & Hess, 1995; Patterson & McCubbin, 1987). The instrument's total score has shown adequate internal consistency: ($\alpha = .72$) and in this study Cronbach's alpha was .86.

Sense of Coherence. The sense of coherence (SOC; Antonovsky, 1987) is the core construct of a complex theoretical model of health (Salutogenesis) and was the dependent variable in this study. An individual's sense of coherence is theorized to be a determinant of the inner and outer environment, which establishes an individual's position on a health/disease continuum. More specifically, SOC is an indicator of a person's ability to manage tension. The supporting theoretical framework posits that an individual's sense of coherence has a direct relationship with the individual's resources (Figure 1-1); thus, the SOC examines an individual's systematic orientation on *how* to stay well and does not necessarily indicate the individual's level of health risk (Eriksson & Lindstrom, 2005).

The 13-item self-report instrument has been measured in children as young as 10 years old. Researchers have reported participants' tendency to score each question as a 1 or 7 (the extremes) on the Likert-scale (Antonovsky, 1987); this tendency was not found in this study. Though the SOC does not separate items into subscales, each question is designed to express one of three components: comprehensibility, manageability, and meaningfulness. A total score is obtained by summing the responses to the 13 items with higher scores indicating greater SOC levels. No cutoff

scores are established for high and low SOC levels because health has been conceptualized to be on a continuum. Furthermore, there may be a point at which high levels of the SOC no longer protects the health of individuals, though there is a lack of evidence in this area (Antonovsky, 1993; Eriksson & Lindstrom, 2005).

Reliability and validity data for the SOC is well established (Antonovsky, 1987; Eriksson & Lindstrom, 2005). Internal consistency is excellent based on SOC-13 data from 127 studies with Cronbach's alpha ranging from .70-.92. In this study the Cronbach's alpha was .86. This measure also shows acceptable test-retest stability from .69-.78 (1 year) and .64 (3 years). The means of the SOC-13 have ranged from 35.39 (SD = 0.10) to 77.60 (SD = 13.80). The convergent validity for predicting health outcomes is discrepant (Eriksson & Lindstrom, 2005). Long-term health perspectives have higher validity in groups of psychiatric, post-traumatic stress, and orthopaedic patients (Eriksson & Lindstrom, 2005). SOC is purported to become stable at age 10 (Antonovsky, 1987); however, data show that the SOC changes over time (Nilsson, 2003). The SOC instrument is thought to be structurally stable, yet the concept appears to be multi-dimensional. Although there is a lack of empirical evidence to support it as a valid instrument for differentiating health outcomes in adolescents, the SOC has been used cross-culturally and has been shown to be a reliable instrument in the measurement of a person's ability to manage tension (Margalit & Eysenck, 1990; Antonovsky, 1993).

Procedure

The Institutional Review Board of the University of Florida granted permission for the study and all recruitment materials. Initial contact with persons who responded to study advertisement was made by telephone and/or email. Potential subjects were

interviewed to see if they met inclusion criteria (Appendix A). Parents of families who met inclusion criteria were given an explanation of the study purpose and general guidelines to complete the study. The parent gave a verbal or written consent via phone or email before a research packet was mailed to them.

Research packets contained the consent form, an instruction sheet, a demographic form and five instruments that were numbered and labeled “A” or “B” to demarcate completion by the sibling or parent. The instruments were placed in a mixed order to reduce study fatigue bias (Portney & Watkins, 2009). The time required for completing the instruments ranged from 45-60 minutes. A postage-paid and a self-addressed envelope to the PI were included in the research packet to facilitate the response rate.

Written instructions advised parents to read the instruments and consent form completely prior to enrolling their typical developing (TD) sibling in the study. The parent’s written consent and TD sibling assent was required and this acknowledged their agreement not to look at the completed instrument without the other participant’s (parent, adolescent) consent. To ensure confidentiality of the data, each research packet was assigned an identification number and upon their return to the researcher, the signed consent and assent form were separated from the instruments. The researcher did not advise parents or counsel siblings based on their responses although families were encouraged within the introductory letter to engage in discussion regarding sibling perceptions upon study completion. A gift card for \$20.00 to Walmart was used as a small incentive to recruit adolescents and was provided with a thank-you note upon return of the study materials.

Statistical Analysis

The theoretical framework of the Salutogenesis Model (Antonovsky, 1987) explains the relationship between human resources to stress and coherence levels using a post-positivist philosophy. Data on self-report instruments were entered into the Statistical Package for the Social Sciences (SPSS) Version 16.0 (Chicago, Illinois).

Data screening

The PI created a database in SPSS using a number keypad and the final dataset was established after an additional 10% of randomly selected participant's data (n=10) were re-entered with an error rate of less than 1%.

Missing data

The sibling dataset had random missing values (n = 85) and no systematic pattern was identified for values used in the analyses. CARS-2 instruments (n = 6) were returned to the parent because they evaluated the TD sibling (evidenced by low raw scores and reported in follow-up communication). In addition, several other adolescent instruments (n = 5) were resent identifying uncompleted pages; all but two forms were returned to the researcher.

For missing data, a code (999, 888) was entered into the raw dataset. After data entry was completed, the researcher returned to the subject's instrument and sought explanation for absent data. A mean value for the missing question was obtained and imputed for random data absences, and a record of each imputation was made. Because of the low number of missing values, this method allowed the participant to remain in the analyses and did not increase the likelihood of Type II error (Fields, 2005).

Analytic Plan

Answering the first three research questions satisfied the primary aim of the study. Univariate and bivariate statistics were calculated to describe the sample across all data points for each model variable. Central tendency and distribution for scale scores on each instrument were calculated. A *T*-test to compare gender and birth order for each major variable was done. A Spearman rho statistic (correlation matrix) examined the demographic variables of sibling age, family size, and age difference to each major variable. In addition, the scale scores of each major variable were related to raw scores on the CARS-2 and the total SOC score. The Friedman test was used to compare the rank of sibling support from a parent, friend, and their brother/sister with ASD.

A test of the model (Figure 1-2) satisfied the secondary aim of the research and was completed after checking assumptions. To do this, all study variables were placed in the model and outliers and multicollinearity were examined by *Df beta* and diagnostics. Assumptions for multiple regression including normality, linearity, and independence of error terms were not violated.

The final research question was answered in two parts. First, a mediating variable, or indirect effect, was examined for resources significant to both the predictor (ASD severity) and the dependent variable (SOC). Next, a moderating or interaction effect, of each resource (coping, support from each relationship, and well being) was analyzed. Finally, significant mediating and moderating relationships were diagrammed and reported.

To examine whether the significant resource acted as a mediating variable, three hierarchical regression models were used to explain the variance of each predictor on the dependent variable beyond that attributed by sibling age and gender. In the first

model the path analysis included: ASD severity regressed on SOC levels (path *a*); Path *b* was examined in separate models by regressing ASD severity on each resource that had a significant correlation; significant resource variables were then regressed separately on the sibling SOC levels to create path *c*. Standardized *Beta* and significance, R^2 Change, and *F* value were reported for each regression model.

Finally, the model was tested for a moderating relationship through a hierarchical regression analysis of the interaction effect separately for each resource scale score. A centered variable for the predictor (ASD severity) was computed by subtracting the predictor variable from its mean score. A centered variable for each moderator was obtained in the same manner. An interaction term was computed by multiplying the centered predictor by the centered moderator. A hierarchical linear regression model was run to examine how much different sibling SOC levels vary in relation to each of their resources and the ASD severity score. In step one, sibling age and gender were entered and in step two the predictive-centered variable was entered (path *a*), followed by the moderator-centered variable (path *b*); and the interaction term (path *c*). For each model, the interaction term was evaluated for significance. A significant *F*-ratio of the interaction term and its clinical nature was reported for each model. A plot of the mean SOC to a high and low number of each resource and a low or high level of ASD severity was graphed to express the phenomenon.

In summary, descriptive statistics were completed and used to answer the first three research questions. Sibling age and gender were compared to the major study variables; a conservative approach was taken reducing the α from .05 to .004 according to the Bonferroni procedure. The study had adequate power to do multivariate analyses

for six predictors and there was a large effect size. The final research question was answered via multivariate analyses.

Scientific Rigor and Ethical Considerations

The study was guided by a post-positivist philosophical approach and findings contribute to the science of adolescent siblings of individuals with ASD. Potential relationships between variables were found through ethical investigative methods and the study was adequately powered to statistically analyze these relationships. The integrity of the study relies on psychometrically sound instrumentation, sample size, data collection procedures, and meeting assumptions for analyses. Children and individuals with disability are vulnerable populations; thus, research investigating these groups must maintain high standards. A discussion of the methods used to maintain these standard and the study limitations are presented in this section.

In this study, self-report by the adolescent sibling provided a direct measure of their life orientation, coping strategies, well being, and support networks. Parents adherence to confidentiality of the TD sibling answers, in a written and signed consent form, allowed siblings to provide honest answers to the instrument questions. A mail-based survey permitted the adolescent sibling sufficient time and added convenience for completion of the instruments. In addition, it limited the participant's bias toward the researcher and further discussion of the study materials (Portney & Watkins, 2009). The benefit of sibling participation was limited to an opportunity for self-inventory through answering the instrument questionnaires. A Walmart gift card in the amount of \$20 was provided to each sibling who returned a completed research packet.

While the study procedures are not overly obtrusive and risk to participants is low, the instruments do inquire about sensitive and personal matters. Thus, several minors

disclosed information that *could* be concerning to their parent. To protect the anonymity of the adolescent sibling, the study responses were separated from the consent forms and kept anonymous. A snapshot evaluation offered in cross-sectional, mail-based research may offer screening data; however, it is inadequate for evaluating a true risk (Achenbach, 1991). Integrity of data was maintained by using an encrypted laptop and transfer of the data to the research team done through a protected server. Written and electronic data will be purged seven years after the dissemination of study findings.

Conclusion

This chapter provides the research design for the investigation. Included in this are description of the target population and each instrument. In addition, the investigative procedures are delineated including the analytical plan. Finally, ethical considerations and scientific rigor for investigating the relationships between sibling resources and severity of ASD were discussed.

CHAPTER 4 FINDINGS

Siblings have a life-long relationship and research on sibling interaction consistently identifies a psychosocial impact on each family member throughout the life cycle. In this investigation, families (N = 96) participated in the study if they had a typically developing adolescent sibling with a brother/sister diagnosed with autism (n = 55), Pervasive Developmental Disorder-Non-Specified (PDD-NOS; n = 19), or Asperger's syndrome (n = 22). To meet the primary study aim, descriptive data provided information regarding the sibling's demographic information, coping strategies, well being, and social support. Multivariate analyses were used to test the health promotion model of Salutogenesis (Antonovsky, 1987) and fulfill a secondary study aim.

This investigation was designed to test the following hypotheses:

1. Sibling age and gender confound the relationship of the major study variables.
2. Support from friends of typically developing siblings is greater than support from parents or from their brother/sister on the autism spectrum.
3. There are significant correlations of scale scores on the A-COPE, NRI-SPV, and YSR to the *ASD severity* score and SOC score in TD adolescent siblings of individuals with ASD.
4. Adolescent coping strategies, network support, and psychological well-being scale scores as measured on the A-COPE, NRI-SPV, and YSR mediate and/or moderate the relationship between severity of ASD as measured by the CARS-2 and life orientation as measured by the SOC in typically developing adolescent siblings of individuals with ASD.

Sample Characteristics

Descriptive data for the family environment are presented in Table 4-1. Parents reported themselves as primarily White (84%) and married (87%). The majority of mothers (62%) and fathers (52%) reported an education beyond high school and income levels > than \$60K/year (65%). Individuals with an ASD were predominantly

male ($n = 77$) and ranged in age from 2-21 years old ($m = 12$, $SD = 4.5$). The ASD diagnoses were categorized as autism (57%), PDD-NOS (20%), and Asperger's syndrome (23%). Adolescent siblings were 11-18 years old ($m = 14.0$, $SD = 2.03$) and mostly female (57%). A majority of TD, adolescent siblings were older (59%) and 47% were first-born children. Family size ranged from 2 to 7 siblings ($m = 2.8$, $SD = 1.04$); and although most siblings were 2 years apart in age, the age difference between siblings ranged from 1 to 12 years ($m = 3.89$, $SD = 2.73$) in the study.

Descriptive Statistics

The primary aim of the study was to characterize adolescent siblings. Descriptive data satisfied this aim and answered the first three research questions. First, we hypothesized that only the demographic variable of TD sibling age and gender would influence associations of the study variables. Central tendency and distribution of the major variables to each demographic variable was examined (Table 4-2). A T-test to compare sibling gender and birth rank (younger/older) was completed. Other demographic variables including sibling age, family size, and sibling age difference were correlated to each of the study variables (Table 4-3). The second hypothesis was that support from friends would be greater than support from their sibling on the autism spectrum or their parent. A Friedman test compared mean scores on the NRI-SPV matrix to answer this question (Table 4-4). Finally, we anticipated a significant correlation between scale scores on each instrument to raw scores of ASD severity and adolescent sibling SOC scores (Table 4-5) and these were examined before testing for a mediating variable. Multivariate analyses using hierarchical regression examined mediating and moderating relationships. These findings are described in this section.

Research Question One

Central tendencies of sibling gender and birth order can be found in Table 4-2. These categorical variables were compared to the major study variables using a *T*-test. Continuous variables of sibling age, family size, and age difference between siblings were correlated to each instrument scale score (Table 4-3). These findings are described below to answer the first research question.

Female siblings perceived a significantly greater amount of support from friends ($t = 3.84, p < .001$) than males. Levels of sibling support ($t = 2.88, p = .005$) and Sense of Coherence scores ($t = 2.19, p = .03$) were greater for females and neared significance. Older siblings had higher scores on the *sibling support* scale than siblings who were younger than their brothers/sisters with an ASD ($t = 2.17, p = .03$).

The age of the TD sibling was correlated only to the *parent support* scale of the NRI-SPV. Younger siblings reported a greater amount of parental support ($r = -.22, p = .03$). Family size ranged between 2 and 7 children and the majority of families had 2 siblings ($n = 48$). Sibling age differences were between 1-12 years (mean = 3.89; $SD = 2.73$) and the majority were 2 years apart in age. Sibling age was the only demographic variable that had a significant association to SOC levels, coping strategies, support scales, or well being.

Research Question Two

The investigator was interested in the amount of support between the adolescent sibling and their parent, brother/sister with ASD, and a same-sex friend. The NRI-SPV provided a scale score of support for each relationship type (range 1-5) and the mean score was compared using the Friedman Test (Table 4-4). Parent support had the highest mean score ($m = 3.67, SD = .69$) and ranked greater than support from a friend

($m = 3.38$, $SD = .70$) and sibling ($m = 2.93$, $SD = .69$). There was a significant difference between ranks [$\chi^2 = 57.80$ ($df, 2$), $p < .001$] and a large association between groups because the scores are not independent of one another.

Research Question Three

The total score on each instrument was correlated to ASD severity and TD sibling SOC scores to answer the third research question (Table 4-5). Only the *total problem* scale of the YSR was correlated to both *ASD severity* ($r = .322$, $p < .01$) and TD sibling SOC scores ($r = -.725$, $p < .01$). Higher levels of ASD severity were associated with greater problems in TD siblings but only 9% of the variance could be attributed. As expected, there was an inverse relationship between *total problems* to TD siblings SOC levels. TD siblings with more problems had lower SOC scores, indicating they had more difficulty managing tension (SOC).

The NRI-SPV *sibling support* scale score was significantly related to TD sibling SOC scores ($r = .246$, $p = .02$). A greater amount of *sibling support* was associated with greater SOC scores but it had a weak and inverse relationship to ASD severity ($r = -.071$, $p > .05$). This finding suggests that positive sibling relationships contribute to TD siblings SOC levels and higher levels of ASD severity result in less sibling support.

In summary, the bivariate analyses of data achieved the study's primary aim of characterizing adolescent siblings and answered the first three research questions. The first hypothesis was confirmed from the data, and age and gender were co-varied in the multivariate analyses. In addition, older, TD siblings reported greater support from their brother/sister with ASD. The second hypothesis was not supported by the study data because mean scores of parent support were greater than mean scores of friend support. Finally, the third hypothesis was partially supported because the *total problem*

scale on the YSR was related to *ASD severity* and TD sibling SOC scores; and, *sibling support* correlated to TD sibling SOC levels. Multivariate analyses tested the model using *total problems* as a mediating variable and each resource as a moderating variable. These findings are described in the following section.

Multivariate Analyses

Multivariate analyses of the data were necessary in order to satisfy the second aim of the study and answer the final research question. The full model was built using hierarchical regression. Sibling age and gender were entered first. These variables were significant [$F=3.828$ (2, 88); $p=.025$] and contributed 8% of variance to the model. Females had significantly higher SOC scores ($\beta=.23$, $p=.03$). Next, all the scale scores were entered. Together, they significantly contributed 50% variance to the model [$F=16.022$ (6, 82); $p<.001$]. Assumptions for multiple regression analyses were examined and no violations of normality, linearity, independence, and homoscedasticity were found. Each resource was analyzed separately as a mediating and moderating variable and these analyses are described below.

Mediating Variable

To test an indirect (mediating) effect of each resource variable on the relationship between ASD severity and adolescent SOC levels, significant correlations must exist between the predictor and dependent variable, predictor and mediating variable, and the mediating variable and the dependent variable (Baron & Kenny, 1986). This was true for only one resource variable – sibling *total problem* scores. To examine the mediating effect, three hierarchical regression models were built (Table 4-6). Sibling age and gender were entered into the model first, followed by the raw score of ASD severity (path *a*). This variable added 6% variance to the model and an inverse relationship

between variables was significant, suggesting that greater levels of ASD severity reduced SOC scores in TD adolescent siblings (Model 1A). ASD severity contributed 10% to the model (path *b*) and significantly predicted the TD sibling *total problem* scale of the YSR [$F = 10.561 (1,90), p = .002$]. TD siblings had greater *problem* scores when there was higher *ASD severity* ($\beta = .32, p < .001$). Finally, the *total problem* score of TD siblings significantly predicted their SOC scores (path *c*). The sibling *total problem* score added 48% variance to the model [$F = 48.553 (2,89) p = < .001$] and there was a strong, inverse relationship ($r = -.707$) suggesting that the greater the *problem* score, the lower the TD sibling's SOC levels.

A mediating variable was identified (Model 1D) because when TD sibling *total problem* score and ASD severity were entered together, ASD severity was no longer significant ($\beta = -.025, p = .74$). These findings mean that *ASD severity* (stress) predicts TD sibling well being, which mediates the relationship between ASD symptom severity and TD sibling SOC scores. Therefore, in the presence of *total problems*, siblings are at greater risk for lower SOC levels. A diagram of this relationship is depicted in Figures 4-3 and 4-4.

Moderating Variable

A variable is identified as being a moderator if the causal relationship between two variables changes as a result of its interaction with the predictor on the dependent variable and significant correlations are not necessary (Baron & Kenny, 1986). Each resource variable – coping, support of parent, support of friend, support of sibling, and well being – was tested separately for an interaction effect and the only significant resource was found to be coping strategies. A moderating variable affects the *direction* or *strength* of the relationship between the independent and dependent variables within

a correlational framework and this is described for the coping variable. A description of the model and *Beta* and significance levels are found in Table 4-3. The path analyses (Figure 4-2) as described by Barron & Kenny (1986) showed insignificant ($>.05$) main effects (path a and path b), and a positive interaction effect (path c).

The moderating model was built in hierarchical regression and sibling age and gender were put in the model first (Table 4-6). These variables contributed 8% of the variance and were significant [$F = 3.941 (2, 89), p < .001$]. Next, the centered predictor, centered moderator, and interaction term were added and the standardized *Beta* coefficients and significance of each path were examined (Figure 4-3). The findings suggest that sibling coping strategies specify the condition under which ASD severity is related to TD sibling SOC levels. The graph (Figure 4-4) depicts the difference in sibling mean SOC scores when there are few coping strategies and low levels of ASD severity compared to when there are many coping strategies and high levels of ASD severity. The finding tells us that sibling coping strategies are necessary in cases of high ASD severity in order for siblings to maintain their sense of coherence.

Summary

The model of Salutogenesis was supported by the data in this sibling group. These associations do not indicate a causal relationship but they support the study aims and provide future direction for experiments using clinical interventions. The final section is a discussion of the dissertation study results, its strengths, limitations, and suggestions for future direction.

Table 4-1. Demographic Characteristics for Sibling Family Environment

Age: (n)	Mean	Median	SD	Range
Father (88)	45.69		7.03	25-62
Mother (96)	42.93		5.60	31-56
Sibling with ASD (95)	12.03		4.46	2-21
Typically developing sibling (96)	13.69	14.00	2.03	11-18
				N (%)
Adolescent sibling				
Female*				57 (59%)
Male				39 (41%)
Individual with ASD				
Female				19 (20%)
Male*				77 (80%)
Ethnicity				
White				81 (86%)
Hispanic				4 (4%)
African American				2 (2%)
Other				7 (7%)
Missing				2 (2%)
Family Size/ Number of children				
Mean (SD)				2.82 (1.04)
One sibling				48 (50%)
Two siblings				26 (27%)
> 3 siblings				22 (23%)
Type of ASD				
Autism				55 (57%)
PDD-NOS				19 (20%)
Asperger's syndrome				22 (23%)
Marital Status				
Married				83 (87%)
Divorced living with s/o				8 (8%)
Divorced not living with s/o				4 (4%)
Widow				1 (1%)
Post Secondary Education				
Mother				62 (65%)
Father				50 (52%)
Employment				
Mothers				62 (65%)
Fathers				23 (24%)
Income				
91,000 or >				41 (43%)
61,000 – 90,000				21 (22%)
31,000 – 60,000				26 (27%)
Below 30,000				7 (7%)
Professional Treatment for ASD				
Yes				73 (76%)
No				23 (24%)

Table 4-1. Continued

	N (%)
TD Sibling Birth Rank to ASD	
Older	61 (63%)
Younger	35 (37%)
TD Sibling Birth Order	
Oldest	49 (51%)
Middle	21 (22%)
Youngest	25 (26%)
Sib Age Difference	
1 year	12 (11%)
2 year	23 (22%)
3 year	21 (20%)
4 – 7 years	24 (23%)
8 -12 years	16 (15%)

* $p < .01$

Table 4-2. Range, mean, standard deviation and median scores on the Sense of Coherence (SOC); Adolescent Coping Orientation for Problem Experiences (ACOPE), Youth Self Report (YSR), and the Network of Relationship Inventory-Social Provision Version (NRI-SPV) to sibling demographics of gender and birth rank.

<i>Range</i>	SOC	ACOPE	YSR	NRI-SPV	NRI-SPV	NRI-SPV
<i>Mean (SD)</i>	(N=96)	(N= 94)	(N=96)	Parent	Friend Support	Sibling
<i>Median</i>				Support	(N=95)	Support
				(N = 96)		(N=96)
Gender (n)						
Male (39)	24-79 57.15 (13.24) 58.00	110-183 154.31 (16.68) 155.00	5-114 48.82 (27.43) 45.00	1.72 - 4.78 3.62 (.60) 3.61	1.61 – 4.33 3.07 (.71) 3.11	1.56 – 4.00 2.70 (.53) 2.78
Female (56)	29-90 63.28 (13.60)* 65.00	94-207 160.51 (22.51) 164.00	6-119 38.90 (25.00) 34.50	1.56 – 4.89 3.72 (.71) 3.83	2.11 – 4.72*** 3.60 (.62) 3.61	1.17 – 4.72** 3.11 (.76) 3.25
Birth Rank (n)						
Younger (34)	32-87 60.40 (12.15) 60.50	117-188 158.85 (16.77) 163.00	5-113 42.49 (26.67) 37.00	1.72 – 4.89 3.68 (.64) 3.75	1.94 – 4.72 3.32 (.73) 3.39	1.56 – 4.00 2.74 (.61) 2.81
Older (59)	24-90 61.02 (14.63) 61.00	94-207 157.42 (22.36) 157.00	6-119 43.18 (26.36) 38.00	1.56 – 4.78 3.68 (.69) 3.83	1.61 – 4.61 3.41 (.69) 3.44	1.17 – 4.72* 3.06 (.73) 3.11

* *p* value < .05

** *p* value < .01

*** *p* value < .001

Table 4-3. Sibling demographic variables of age, age difference, and family size are correlated to scale scores of coping, support, well being, and sense of coherence variables. The instruments include: Adolescent Coping orientation for Problem Experiences (ACOPE), Network of Relationship Inventory-Social Provision Version (NRI-SPV), Youth Self Report (YSR), and Sense of Coherence (SOC)

Spearman's rho Correlation Matrix									
Variable	1	2	3	4	5	6	7	8	9
1) Sibling Age	-								
2) Sibling Age Difference	.15	-							
3) Family Size	-.11	.16	-						
4) Coping Strategies (A-COPE)	.14	.15	-.09	-					
5) Parent Support (NRI-SPV)	-.22*	-.02	-.09	.15	-				
6) Friend Support (NRI-SPV)	-.04	-.03	-.18	.43**	.15	-			
7) Sibling Support (NRI-SPV)	-.18	-.06	-.05	.18	.39**	.38**	-		
8) Total Problem Behaviors (YSR)	.00	.07	.15	.01	-.02	-.07	-.16	-	
9) Sense of Coherence (SOC)	-.15	-.01	-.18	.08	.12	.10	.25*	-.68**	-

* $p < .05$

** $p < .01$

Table 4-4. Results of Friedman Test are shown. Siblings perceived higher levels of support from a parent, friend, and sibling respectively

<i>Ranks of Sibling Support</i>	
Variable	Mean Rank
Support Parent	2.48
Support Friend	2.11
Support Sibling	1.41

Table 4-5. Correlations for scale scores on the Youth Self Report (YSR), Adolescent Coping orientation for Problem Experiences (ACOPE), and the Network of Relationship Inventory-Social Provision Version (NRI-SPV) to Severity of Autism Spectrum Disorder (ASD) measured by Child Autism Rating Scale-2nd Ed. and to Sense of Coherence (SOC) scores.

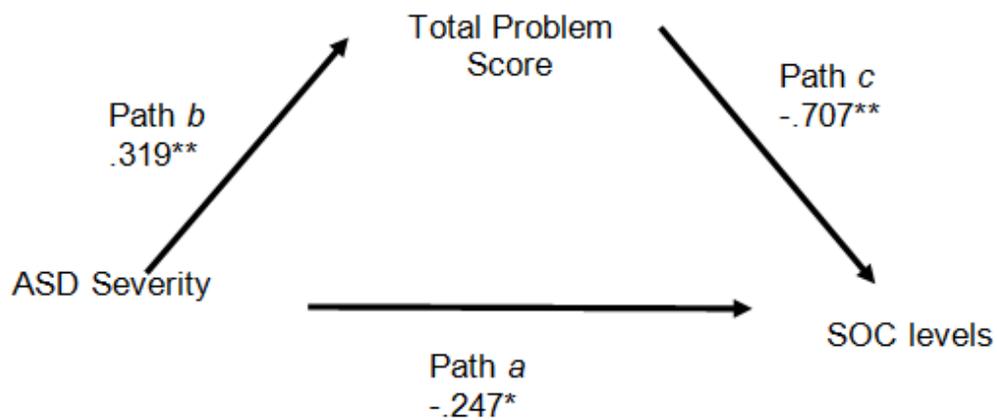
<i>Significant Correlations of ASD severity and SOC scores to Major Study Variables</i>		
	ASD Severity CARS-2	Life Orientation SOC
Coping Strategies (A-COPE)	-.045	.080
Support (NRI-SPV)		
Parent	-.025	.122
Friend	.088	.102
Sibling	-.071	.246*
Total Problem Behaviors (YSR)	.322**	-.725***

* $p < .05$
 ** $p < .01$
 *** $p < .001$

Table 4-6. Hierarchical regression models are examined to test the model. Significant mediating and moderating variables are identified. Data displayed in Model 1 is derived from total problem scale on the Youth Self Report (YSR). ASD severity was the raw score on the Child Autism Rating Scale -2nd Ed. (CARS-2). Coping strategies was obtained from the scale score of the Adolescent Orientation for Problem Experiences (A-COPE).

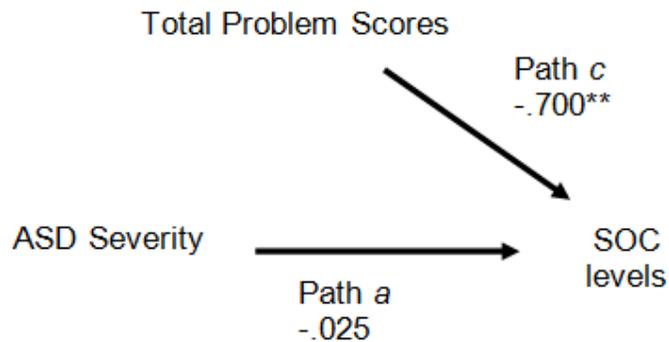
<i>Test of Model/Research Question Four</i>				
Model/Predictor	β	p -value	R^2 Δ	F -change
<i>Mediating Model for Total Problems</i>				
Model 1A (path a)	.247	.01**	.06	6.354**
ASD severity			.10	10.561**
Model 1B (path b)	.319	.002**		
ASD severity			.48	99.517***
Model 1C (path c)	-.71	***		
Total Problems			.48	48.553***
<i>Model 1D (Indirect Effect)</i>				
ASD severity	.025	.743		
Total Problem	-.70	***		
<i>Moderating Model for Coping</i>				
Model 2A (path a)			.05	5.107*
Centered Predictor	-.19	.03*		
Model 2B (path b)			.01	.780
Centered Moderator	.114	.251		
Model 2C (path c)			.07	7.339**
Interaction (severity X total problems)	.263	.008**		

* $p < .05$
 ** $p < .01$
 *** $p < .001$



Mediating Model

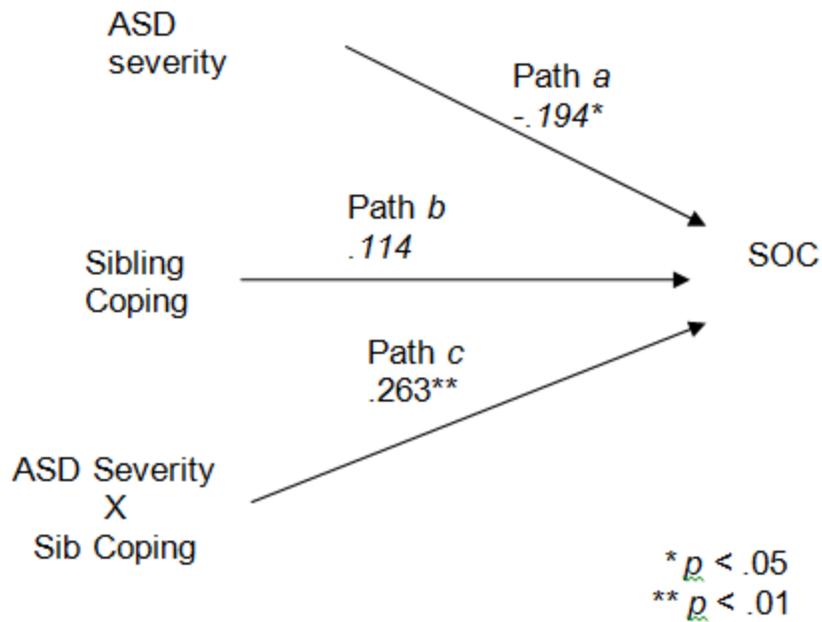
Figure 4-1. Beta weights and significance for mediating model: path a) the predictor (ASD severity = raw score of Child Autism Rating Scale) to outcome (Sense of Coherence); path b) predictor (ASD severity) on mediator (total problem score on the Youth Self Report); path c) mediator (total problem) to outcome (Sense of Coherence).



* $p = < .01$, ** $p = < .001$

Mediating Model

Figure 4-2. Shows change in Beta and significance of predictor to outcome when predictor and mediator are regressed on SOC levels.



Moderating Model for Coping Strategies

Figure 4-3. A path analyses to test for interaction (moderating) variable. Beta weights and significance for the centered predictor variable (ASD severity) obtained from the Child Autism Rating Scale, centered moderator variable (coping strategies) obtained from the Adolescent Orientation for Problem Experiences, and interaction term obtained by multiplying centered predictor and centered moderator (path c).

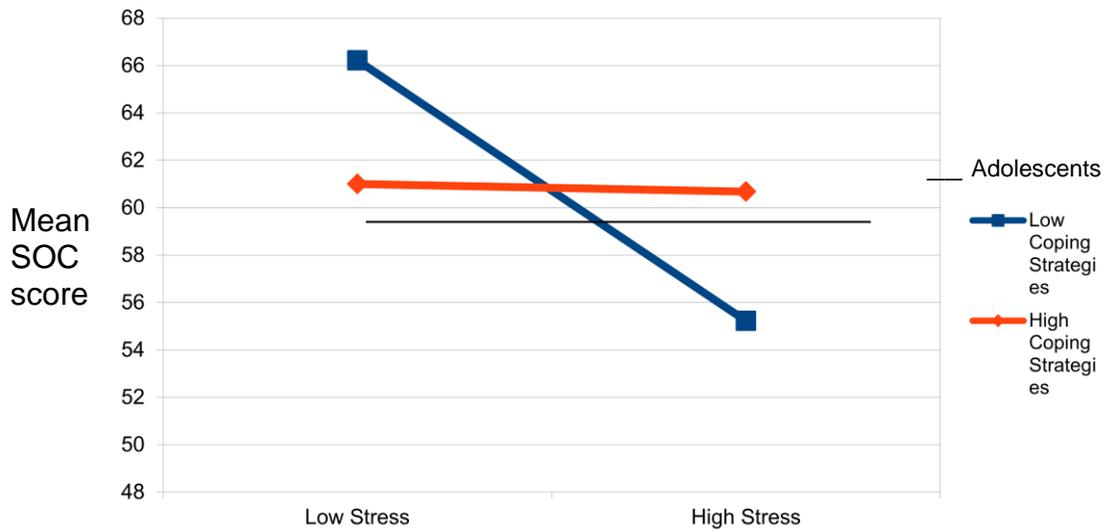


Figure 4-4. Shows the interaction of severity of autism spectrum disorder (ASD) and coping strategies on typically developing siblings' Sense of Coherence (SOC) scores. SOC levels are significantly reduced when ASD severity is high and coping strategies are low. A reference line shows mean SOC score of Israeli adolescent boys (Margalit & Eysenck, 1990).

CHAPTER 5 DISCUSSION

This study's primary aim was to characterize adolescent siblings of individuals with an autism spectrum disorder (ASD) by describing their resources and sense of coherence (SOC). In a secondary study aim, the model of Salutogenesis (Antonovsky, 1987) was tested. A discussion of the study findings and their relation to the published research are included in this chapter. In addition, the clinical and theoretical implications related to the study findings are addressed, and recommendations for future research are provided. Finally, the implications for nursing are described.

Findings Related to Previous Research

Major variables from previous research of siblings of individuals with an ASD include sibling adjustment and relationship quality as well as social support and coping strategies. First, data related to sibling demographics, or attributes are described. Next, characteristics of siblings' coping strategies, relationship networks, and well being are related to earlier research. Finally, in this section, the conceptual framework of three constructs – stress, resources, and sense of coherence – and data supporting them are presented.

Sibling Attributes

Sibling age and gender were covaried in the study because the stages of child development and sibling gender are known to influence individual perceptions of well being, support, and coping strategies (Glasberg, 2000, Giallo & Gavidia-Payne, 2006; Gupta & Singhal, 2005, McHale et al., 1986; Verte et al., 2003). In this study, a cohort of adolescent siblings, 11-18 years old participated ($m = 14.0$ years, $SD = 2.3$); age and gender contributed 8% of the variance to the full model.

It is possible that categories of early, middle, and late adolescence would provide more information although no cut-off points were used to categorize the scale level variable. Based on the correlative findings, older siblings held more positive views of their siblings than younger (coded 0) TD siblings ($t = 2.17, p = .03$). This finding is inconsistent with McHale (2001) whose research team investigated an adolescent group from two-parent families and found younger siblings had less conflict. It has also been reported that older siblings have better relationships with the child with ASD (Hastings, 2003; Kaminsky & Dewey, 2001; Macks & Reeve, 2007; Orsmond et al., 2009). Consistent with this, the study sample had a greater number of siblings who were older ($n = 61$) and their birth rank was significantly different ($t = 2.17, p < .03$) in relation to *sibling support*. The age difference between siblings was examined; and, while 40% ($n = 40$) of the siblings were four or more years apart in age, this did not correlate with the major study variables. Orsmond et al. (2009) found that siblings closest in age had greater levels of depression; therefore, creating a cutoff point and categorizing the *age difference* variable may have provided more information.

The majority of siblings were female (60%) and they reported higher SOC scores ($m = 63.28, SD 13.60$) and lower total problem scores than the males ($m = 57.15, SD 13.24$). They also perceived significantly ($p < .001$) greater amount of support from parents and friends. These findings are consistent with Kaminsky & Dewey (2001) and McHale & Gamble (1986) who described female siblings of a person with disabilities as having greater relationship quality with their parents and sibling than the male comparison group. Several explanations for this include the fact that females may exhibit better social skills and/or they have less phenotypic expression of genetic

susceptibility to ASD (Constantino, et al., 2006; Seltzer, et al., 2004). Screening for a benign autism phenotype (BAP) was not completed for study participants, although TD siblings were excluded if parents reported they had a diagnosed learning disability.

The number of children in the home determined family size. Fifty percent of the adolescent siblings (n = 48) reported having only their brother/sister with ASD; 25% had two siblings; and the remaining study participants (n=22) had three or more siblings. Despite this variability, sibling family size did not significantly correlate to the major study variables. This finding is in contrast with Kaminsky & Dewey (2002) who reported that large family size was associated with improved siblings' adjustment scores. Further data analyses are necessary to determine the impact of family size on sibling resources and SOC.

Coping Strategies

The Salutogenic model (Antonovsky, 1987) is a coping theory and was used as the framework of this study. Total scores on the Adolescent Coping Orientation for Problem Experiences (A-COPE; Patterson & McCubbin, 1987) had a significant interaction effect with ASD severity ($\beta = .263, p < .01$) and supported the theory. Therefore, TD siblings who had brothers/sisters with high levels of ASD severity (higher stress) had higher SOC levels if they utilized a greater number of coping strategies.

The A-COPE was not utilized in prior research investigating siblings of individuals with ASD and this makes it difficult to compare findings related to TD sibling coping. In a qualitative investigation, Dellve et al., (2000) categorized coping strategies from siblings of two different types of learning disability (one was Asperger's) and found that strategies were related to contextual concepts of sibling *requirements* and sibling *concerns*. Siblings had a 'self-concerned' focus, 'family-oriented' focus, or 'sibling-

oriented' focus and their strategies were based on the balancing and understanding of these. Ross & Cuskelly (2006) found 'emotional regulation' and 'wishful thinking' as the two most common coping strategies regardless of the type of sibling interaction. Finally, Orsmond (2007) found siblings had better relationships with their brother/sister on the spectrum when they engaged in problem-focused rather than emotion-focused coping strategies. These comparative studies on coping strategies substantiate that the demands of ASD are great and provide information necessary to design future intervention studies. For example, siblings may find that they are better able to cope if they are taught to identify and articulate the problems encountered from having a sibling with ASD rather than just respond to them emotionally. This could have important positive implications over a lifetime of interactions with their sibling with ASD.

Relationship Networks

A matrix of support from a parent, same-sex friend, and their sibling with an ASD was useful for characterizing TD, adolescent siblings because the data were not consistent with other sibling groups. The reasons remain unclear but several explanations are offered.

Adolescents have previously reported greater levels of perceived support from friends than from parents (Stice, Ragan, and Randall, 2004, Noack & Buhl, 2004) and greater support from siblings than friends (Furman & Buhrmester, 1985). Consistent with Kaminsky & Dewey (2002), *parent support* scores were higher than *friend support* scores especially among females, although only *sibling support* was significantly correlated ($r = .24, p = .02$) to TD sibling SOC scores. Despite these associations, *sibling support* did not predict TD sibling SOC levels and this was likely because sibling gender was controlled by hierarchical regression analysis. Finally, siblings who

reported greater levels of *sibling support* also reported higher *parental support* ($r = .391$, $p < .001$). These findings are consistent with Orsmond et al. (2009) who reported that adult siblings who regarded their sibling relationship as positive also reported higher levels of parental support.

Because siblings are receiving greater support from parents than friends, the study reveals that parents are working hard to meet the TD sibling demands and those related to ASD. Tzoy, et al., (2004) found lower means scores from parents in acquiring social support, seeking spiritual support, and passive appraisal when compared to normative data. Consistent with previous research (Smith & Elder, 2010), TD siblings are influenced by the behavior of parents; thus, their expression of social behavior may be similar. In addition, care-giving demands (Dyson, 1996) and deficits in sibling's social skills (Gupta & Singhal, 2005) may interfere with the TD sibling social interactions outside the home. In consideration of these findings from previous research and Orsmond's data (2009), which found social support from family members and friends greater in adolescents ($p < .001$) than in the adult group, interventions must begin early in the sibling's lifetime. Participation in group sports or activities could be very beneficial for improving social skills, nurturing the sibling relationship, and developing support from friends.

Sibling Well Being

Psychological well being, measured by the *total problem* scale on the Youth Self Report (Achenbach, 2001), was consistent with adolescent siblings in the general population (Kim, et al., 2007). When *total problem* scores were converted to *T* scores, 16% of the sample was noted to be at risk and 84% were not at risk. Although male siblings reported a greater number of problems, there were no significant gender

differences ($t = -1.836, p = .07$). Consistent with prior research, severity of the ASD was significantly correlated ($r = .32, p < .01$) with the TD sibling's total problem score (Benson, 2007; Hastings, 2007). Of interest, this association was stronger than the relationship of ASD severity to the TD siblings' SOC scores ($r = -.21, p < .05$). Sibling's *total problem* scores were found to have a strong and significant association ($r = -.725, p < .001$) to the sibling's life orientation as measured by the Sense of Coherence (SOC; Antonovsky, 1987) instrument. Furthermore, it mediated the relationship of ASD severity as measured by the Child Autism Rating Scale-2nd Edition (CARS- 2; Schopler et al., 2010) to sibling SOC levels. This finding indicates that TD adolescent siblings who have more problems are influenced to a greater degree by the ASD severity. No interaction effect was found.

In summary, sibling demographics of age, gender, birth rank, sibling age difference, and family size were examined by analyzing each to sibling coping, support, and well-being. Female siblings consistently reported significantly ($p < .001$) greater levels of relationship quality than their male counterparts. Both genders utilized a greater number of coping strategies when ASD severity levels were high. The number of adolescent *total problems* and sibling SOC levels had a significant and inverse relationship ($r = -.725, p < .001$). This finding makes theoretical sense because sibling resource deficits (higher problem scores) reduce the sibling's ability to have a positive disposition and manage tension (SOC). A further discussion of the theoretical framework follows.

Conceptual Framework

The model of Salutogenesis (Antonovsky, 1987) is recursive to the sense of coherence concept (Figure 1-1). In this study, the model was modified and the sense of

coherence (SOC) was the dependent variable (Figure 1-2). Three concepts – stress, resources, and life orientation – were operationalized to examine the model's relationships. It was hypothesized that ASD severity (the stressor) was related to the sibling's life orientation (SOC). Furthermore, the model posits that sibling resources can be predicted by the severity of the stressor and sibling SOC level.

Stress

Previous research has compared ASD severity to parental stress, sibling adjustment, and sibling relationship quality (Davis & Carter, 2008; Fisman et al., 2000; Hastings, 2003; Orsmond, 2007). A diagnosis of *Autism Spectrum Disorder* by definition assumes a wide variety of symptoms in three general areas of function: communication, sensory, and social function (CDC, 2010). Lardieri, Blacher & Swanson (2000) and other researchers concluded that behaviors associated with the disorder make it more difficult for siblings and parents to adapt. In contrast, Pilowsky et al. (2004) found no difference when comparing siblings of ASD to siblings without a disabled brother/sister. These researchers reported that 87% of siblings of individuals with ASD had no adjustment difficulty and their findings are supported by data from this study.

Clearly, ASD impacts each family member and siblings are no exception. The mean score (34.54, $SD = 7.84$) on the Child Autism Rating Scale-2nd Ed. (CARS-2; Schopler et al., 2010) indicates that the individual with ASD had symptoms for a moderate impairment in communication, social, and behavioral indices in the study sample. There was a significant and inverse correlation to sibling SOC scores ($r = -.213$, $p = .03$) suggesting that higher levels of ASD severity reduced TD sibling SOC scores. ASD severity was not found to be a major predictor of sibling *coherence*, *total problems*, or *sibling support* because the raw score of *ASD severity* contributed only 5% of

variance to the TD sibling SOC score; 9% to the sibling *total problem* score, and 4% to *sibling support* scores. Thus, the majority of siblings are adapting, managing, and relating well to their brother/sister with ASD.

Resources

Each sibling resource was correlated to ASD severity and sibling SOC scores. Only siblings' total problem score was significantly ($p < .05$) related to ASD severity. The scores for sibling coping strategies, support from their brother/sister with ASD, and siblings' total problems had significant associations ($p < .05$) to their SOC scores. It makes theoretical sense that resources predict a sibling's ability to manage tension (SOC); it is more difficult to explain how the ASD severity predicts sibling resources because severity remains fairly stable over time. Rather, sibling resources are more likely predicted by the ASD severity. While siblings' *total problems* and coping scores were associated, a bidirectional relationship is likely, and clinically, we cannot generalize the study findings due to the cross-sectional study design.

Sense of Coherence

The TD siblings' ability to manage tension, measured by their SOC scores, was the dependent variable in the theoretical framework. It was significantly related to *ASD severity* ($r = -.21, p = .03$), as measured on the CARS-2; the *total problem* score ($r = -.676, p = .003$) on the YSR (Achenbach, 2001), and *sibling support* ($r = .246, p = .02$) on the NRI-SPV (Furman & Buhrmester, 1994). Antonovsky & Sagy's (1986) research reported that adolescent boys had greater SOC scores than their female peers. In this study sample, girls had greater scores than boys ($t = 2.19, p = .03$). The mean SOC score in this study sample was 60.79 ($SD = 13.72$) and this finding shows that siblings

are managing the stress of ASD quite well. While this is reassuring data, the resources investigated in the study could account for only 50% of the variance.

In summary, the conceptual framework of the Salutogenesis model guided the research and was supported by data from the study but was limited by the research design. Stress was operationalized as ASD severity and, as expected, was significantly ($p < .05$) related to sibling SOC scores. Although stress (ASD severity) predicted one sibling resource, *total problem* scores, it is likely that a bidirectional relationship exists.

Strengths, Limitations, & Directions for Future Research

This investigation contributed to the science of siblings of individuals with an autism spectrum disorder by describing adolescent coherence levels, coping strategies, relationship networks, and well being. In addition, the associations between stress, sibling resources and coherence were explored. Theoretical underpinnings provided a meaningful data analyses although additional sibling resources that correlate with sibling SOC levels need to be identified in future research. A discussion of these follows.

Strengths

Few studies have investigated adolescent siblings of individuals with an ASD and rich data was obtained in a direct self-report methodology that has been shown to be more accurate than parent report (Verte et al., 2003). A large homogenous group throughout the United States completed mail-based surveys providing siblings sufficient time and confidentiality as evidenced by signed consent and low amount of missing data. Adequate statistical power helped to ensure meaningful data of multivariate analyses to answer the research questions. Furthermore, the theoretical model of Salutogenesis (Antonovsky, 1987) was supported by the study data. Thus, sibling

resources that are significant to their SOC levels can be utilized to develop clinical interventions in future experimental research.

Limitations

A cross-sectional study design cannot evaluate causation between relationships; thus, ASD severity as a predictor of each sibling resource is based on theory alone. Although there was a correlation and indirect effect of the TD sibling problems on the relationship of ASD severity to sibling SOC, one cannot generalize the findings because ASD severity is fairly stable and would need to be measured in a longitudinal design to establish its predictability.

A second limitation of the study was inclusion/exclusion criteria (Appendix A). Although siblings with cognitive learning disabilities were excluded, siblings with psychiatric and chronic medical conditions were not. These conditions may indicate the presence of the benign autism phenotype (BAP), or a genetic inheritance of features that resemble one or more of the characteristics of ASD but are not severe enough to be diagnosed as ASD (Mazefsky et al., 2008; Pilowsky et al., 2004). Earlier studies have shown a relationship between the BAP and adjustment in siblings of individuals with ASD (Orsmond & Seltzer, 2009). In order to better understand to what extent the environment influences siblings, siblings from families with more than one sibling on the spectrum could have been excluded (Virkud et al., 2008).

Self-report instruments as the only data source can limit the accuracy of the study findings and is a limitation of this study. Multiple data sources can be obtained (direct observation, parent/teacher report) to address this but due to financial and time constraints, self-report was the only method utilized in data collection. The use of required parental consent can introduce bias into sample selection and also limit the

generalizability of the research findings (Portney & Watkins, 2008). However, the nature of the study variables required parental consent for minor-age siblings. In addition, a mail-based survey cannot guarantee independent completion of the study instruments. It is possible that a non-sibling completed the survey. This factor is not accounted for in the studies analyses and therefore is a study limitation.

The composition of the sample is a final study limitation. The use of a non-random sample can limit external validity of the research findings, and a purposive-convenience sample was utilized to maximize the number of study participants. Although the study reached adequate power for statistical analyses (N=96), its findings cannot be generalized to all adolescent siblings of individuals with a brother/sister on the autism spectrum because there was inadequate representation of minority groups or siblings from lower socioeconomic status.

Future Direction

Two implications for future research are offered. The first suggestion is based on study findings and the second is offered based on what was not accomplished in this study.

Coping strategies was a moderating variable and siblings required a greater number of them if their brother/sister had high ASD severity. The analysis of coping was limited to the total score rather than specific subscales. The majority of research in children and adolescents has focused on differences between individuals within a population in order to examine what types of coping contribute to successful adjustment (Blount, et al., 2008; Skinner & Zimmer-Gembeck, 2007). A future direction for investigation would employ a quasi-experimental research design and systematically test specific coping strategies under consistent conditions.

The study model identified that the sibling resources (coping, well-being, and support networks) together contributed approximately 50% of the variance and *well-being* was the greatest factor. Other resource variables that may have added to the variance and the science include the amount of sibling care giving, knowledge of the ASD, and an indicator for sibling self-esteem and/or self-concept.

This cross-sectional investigation identified sibling resources that correlated to ASD severity and TD sibling SOC levels. A next step in understanding this group requires further investigation of the instrument subscales. This information will help to develop an intervention for enhancing TD sibling relationships with their sibling on the spectrum and/or their friends. In addition, a longitudinal, quasi-experimental research design will be helpful in determining the impact of ASD severity on sibling SOC levels.

Conclusion and Implications for Nursing

Siblings appear to have bonds that are unique from other relationships and may play an important role for an individual with ASD. In clinical practice today, it is unusual for siblings to receive interventions specifically for them. Generally speaking, the treatment plan is limited to parents. This is unfortunate since genetics, common birth-right, and similar environmental backgrounds are contributing factors that influence their interactions and should be evaluated when providing comprehensive care within the family environment.

Siblings of individuals with ASD have surprisingly high levels of coherence and this author believes it stems from their support and protection of their brother/sister with ASD. In this study, parents were found to be highly supportive of the TD sibling but they already have great demands on them. Thus, the TD siblings play an important role in

the treatment and management of the ASD and may require assistance from health care professionals or sibling support groups.

The study findings did not identify specific criteria for intervention but they did support previous research that TD siblings who are younger, male and who have brother/sisters with high ASD severity are at the greatest risk for having difficulty managing tension. Nurses are well positioned to help families identify and address the needs of TD siblings as well as family members with ASD. Furthermore, they can participate in future research designed to evaluate sibling interactions and support networks. This is vital for improving sibling well being and enhancing the quality of a unique sibling bonds that can last a lifetime.

APPENDIX A QUESTIONNAIRE

PLEASE ANSWER, “YES” OR “NO” AFTER EACH QUESTION:

1. Is there a family member who has a diagnosis of autism, Asperger syndrome, or pervasive developmental disorder – non-specified (autism spectrum disorder)?
2. Are you the legal guardian of the individual with ASD?
3. Are you the legal guardian of the adolescent sibling?
4. Do all the family members read and write English?
5. Is the adolescent brother or sister (sibling) between 11-18 years old?
6. Have they lived in the same home with the family member who has an autism spectrum disorder for a minimum of one year?
7. Has the adolescent sibling been diagnosed with a learning disability, chronic medical condition, or psychiatric diagnosis?

Positive responses to the above questions with the exception of question 7 meet the study inclusion and exclusion criteria.

Inclusion criteria for typically developing adolescent siblings include:

- A written consent from their legal guardian;
- The primary caregiver (parent) of the individual with ASD and the adolescent are able to read and write in English;
- The adolescent may be a biologic or non-biologic sibling but must currently reside or has had previous residence of \geq one year with their sibling with ASD.

Exclusion criteria include:

- The adolescent sibling has a learning disability
- Only one adolescent sibling enrolled per family
- A twin sibling

APPENDIX B
INSTRUMENTS

Demographic Information

Please complete the following information about all members of your household:

	YES or NO	GENDER	AGE
Father			
<hr/>			
Mother			
<hr/>			
Child			
<hr/>			
Child			
<hr/>			
Child			
<hr/>			
Child			
<hr/>			
Child			
<hr/>			

Have any children in your family been diagnosed with autism, a language disorder, learning disability, developmental problem, attention problems or a chronic illness?

Yes _____ No _____

If YES, what specific illness (es) or type of problem (s) and which child (ren) is affected?
CHILD'S AGE Type of Problem

What is your race or ethnic background?

Are any of your children adopted? YES _____ NO _____

If YES, please specify which child (ren) is/are adopted.

Child (ren)'s AGE _____

What is your family income?

_____ below 30,000 _____ 61,000 to 90,000
_____ 31,000 to 60,000 _____ 91,000 or above

FOR MOTHER: What is your present marital status? (please check all that apply)

_____ Married _____ Separated
_____ Living with someone _____ Never married and not living with someone
_____ Divorced _____ Widowed

From the list below, please indicate the highest level of education that you have completed

- a) Some high school
- b) High school diploma
- c) Some post-secondary, but no diploma or degree
- d) Post-secondary diploma (ex. Technical school)
- e) University degree

What is your occupation?

Are you currently employed? Yes _____ No _____

Are you working extra hours to afford the care of your child's disability? Yes _____ No _____

Are you involved in a professional treatment plan for your child? Yes _____ NO _____

If these include treatments include therapy, about how many hours in a **week** do you spend administering the therapy or providing accommodations for your child to receive them? (ex. practicing new lessons, travel, waiting)

Aside from your time spent in the above question, about how many hours in a **day** are you involved with extra care your child needs secondary to his autism?

FOR FATHER:

What is your present marital status? (Please check all that apply)

- | | |
|---------------------------|---|
| _____ Married | _____ Separated |
| _____ Living with someone | _____ Never married and not living with someone |
| _____ Divorced | _____ Widowed |

From the list below, please indicate the highest level of education that you have completed

- a) Some high school
- b) High school diploma
- c) Some post-secondary, but no diploma or degree
- d) Post-secondary diploma (ex. Technical school)
- e) University degree

What is your occupation?

Are you employed? Yes _____ No _____

Is your child participating in therapy related to their disability?

Yes _____ No _____

Are you involved in the treatment plan? Yes _____ NO _____

About how many hours in a **week** do you spend related to these therapies? (Ex. Driving, practicing new lessons, etc...) _____

Aside from your time spent in the above question, about how many hours in a **day** are you involved with **extra** care your child needs secondary to his autism? _____

The Network of Relationships Social Provision Version
NRI-SPV (Furman & Buhrmester, 1985)

ID # _____

Everyone has a number of people who are important in his or her life. These questions ask about your relationships with each of the following people: your parent, your brother/sister with disability, and a same sex friend.

The first questions ask you to identify your parent, sibling, and friend about whom you will be answering the questions.

1. Circle the **parent figure** you will be describing.

- A. Biological/Adopted Mother
- B. Step-Mother (or Father's Significant Other)
- C. Biological/Adopted Father
- D. Step-Father (or Mother's Significant Other)
- E. Other _____

2. How old is your sibling with an autism spectrum disorder? _____ years old.

3. Now we would like you to choose the most important same-sex friend you have now. Do not choose your sibling. How long is the friendship? _____ years _____ months (*please fill in numbers*).

Now we would like you to answer the following questions about the people you have selected above. Sometimes the answers for different people may be the same but sometimes they may be different.

9. How much free time do you spend with this person?

	Little or None	Some- what	Very Much	Extremely Much	The Most
Parent	1	2	3	4	5
Sibling	1	2	3	4	5
Friend	1	2	3	4	5

Description. The NRI-SPV (Furman & Buhrmester, 1985) has ten scales with three items per scale. It assesses 7 support features, 2 negative interaction features, and relative power.

Scales

Companionship (COM)

- 9 How often do you spend fun time with this person?
- 19 How often do you and this person go places and do things together?
- 29 How often do you play around and have fun with this person?

Conflict (CON)

- 10 How often do you and this person disagree and quarrel with each other?
- 20 How often do you and this person get mad at or get in fights with each other?
- 30 How often do you and this person argue with each other?

Instrumental Aid (AID)

- 11 How much does this person teach you how to do things that you don't know?
- 21 How much does this person help you figure out or fix things?
- 31 How much does this person help you when you need to get something done?

Antagonism (ANT)

- 12 How much do you and this person get on each other's nerves?
- 22 How much do you and this person get annoyed with each other's behavior?
- 33 How much do you and this person hassle or nag one another?

Intimate Disclosure (DIS)

- 13 How often do you tell this person things that you don't want others to know?
- 23 How often do you tell this person everything that you are going through?
- 33 How often do you share secrets and private feelings with this person?

Nurturance (NUR)

- 14 How much do you help this person with things she/he can't do by her/himself?
- 24 How much do you protect and look out for this person?
- 34 How much do you take care of this person?

Affection (AFF)

- 15 How much does this person like or love you?
- 25 How much does this person really care about you?
- 35 How much does this person have a strong feeling of affection (loving or liking) toward you?

Reassurance of Worth (WOR)

- 16 How much does this person treat you like you're admired and respected?
- 26 How much does this person treat you like you're good at many things?
- 36 How much does this person like or approve of the things you do?

Relative Power (POW)

- 17 Who tells the other person what to do more often, you or this person?
- 27 Between you and this person, who tends to be the BOSS in this relationship?
- 37 In your relationship with this person, who tends to take charge and decide what should be done?

Reliable Alliance (ALL)

- 18 How sure are you that this relationship will last no matter what?
- 28 How sure are you that your relationship will last in spite of fights?
- 38 How sure are you that your relationship will continue in the years to come?

often

7. Doing the things you do every day is:

- 1 • 2 • 3 • 4 • 5 • 6 • 7
A source of deep pleasure and satisfaction A source of pain and boredom

8. Do you have very mixed up feelings and ideas?

- 1 • 2 • 3 • 4 • 5 • 6 • 7
Very often Very seldom or never

9. Does it happen that you have feelings inside you would rather not feel?

- 1 • 2 • 3 • 4 • 5 • 6 • 7
Very often Very seldom or never

10. Many people-even those with a strong character-sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?

- 1 • 2 • 3 • 4 • 5 • 6 • 7
Never Very often

11. When something happened have you generally found that:

- 1 • 2 • 3 • 4 • 5 • 6 • 7
You over-estimated or under things in the

Adolescent Coping Orientation for Problem Experiences
A-COPE (McCubbin & Patterson, 1987)

Scale items:

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

1. Go along with parent's 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
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 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 ("warm fuzzies") 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 necessarily prescribed by a doctor)
25. Organize your life and what you have to do
26. Swear
27. Work hard on school work or school projects
28. Blame others for what's going on
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, biking, etc.)
34. Get professional counseling (not a school teacher or school counselor)
35. Try to keep up friendships or make new friends
36. Tell yourself the problem(s) 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 (Space Invaders, Pac-Man), pool, pinball, etc.
54. Do a strenuous physical activity (jogging, biking, etc.)

USE THE FOLLOWING RESPONSE CATEGORIES.

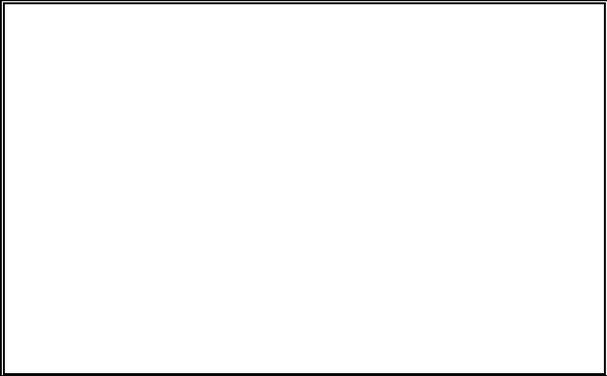
1. Never
2. Hardly
3. Sometimes
4. Often
5. Most of the time

file:///C:/CHIPTS_local/assessment/Assessment_Instruments/Assessment_files_new/assess_acope.htm (2 of 3) [4/7/2003 10:18:11 AM]
CHIPTS - Adolescent Coping Orientation for Problem Experiences

APPENDIX C
INFORMED CONSENT FORM



INFORMED CONSENT FORM
to Participate in Research



INTRODUCTION

Name of person seeking your consent: _____

Place of employment & position: _____

This is a research study of adolescent siblings of individuals with an autism spectrum disorder.

Could participating in this study offer any direct benefits to you? No as described on page 4.

Could participating cause you any discomforts or are there any risks to you? No, as described on page 4.

Please read this form which describes the study in some detail. I or one of my co-workers will also describe this study to you and answer all of your questions. Your participation is entirely voluntary. If you choose to participate you can change your mind at any time and withdraw from the study. You will not be penalized in any way or lose any benefits to which you would otherwise be entitled if you choose not to participate in this study or to withdraw. If you have questions about your rights as a research subject, please call the University of Florida Institutional Review Board (IRB) office at (352) 273-9600. If you decide to take part in this study, please sign this form on page 8 and/or 9.

GENERAL INFORMATION ABOUT THIS STUDY

1. **Name of Participant ("Study Subject")**

2. What is the Title of this research study?

The Relationship between Resources and Sense of Coherence in Adolescent Siblings of Individuals with Autism Spectrum Disorder

3. **Who do you call if you have questions about this research study?**

Laura O. Smith at 727-641-3890 or email lauraosmith@ufl.edu

4. **Who is paying for this research study?**

The sponsor of this study is the University of Florida

5. **Why is this research study being done?**

We do not know very much about the pre-teen and teenaged brothers and sisters of children with autism spectrum disorders (ASD). The purpose of this research is to describe their psychological well-being (such as frustrations, worries, behaviors, or other feelings), their support networks (which include meetings or friends where they can talk to others about their living situations and the good and bad parts of their every-day living situations), their coping mechanisms (strategies used to feel better about what they may believe in a difficult situation), and coherence levels (their ability to manage tension).

You are being asked to be in this research study because you have a child and/or a brother or sister with autism, Asperger's syndrome, or Pervasive Developmental Disorder – Non-specified. For the rest of this consent form, we will refer to your brother or sister's problem as an ASD.

WHAT CAN YOU EXPECT IF YOU PARTICIPATE IN THIS STUDY?

6. What will be done as part of your normal clinical care (even if you did not participate in this research study)?

Normal clinical care is not being offered as part of this study.

What will be done only because you are in this research study?

Part I – The legal guardian or parent of the child with ASD.

If you are the parent or legal guardian, you will be asked to complete two forms. A demographic information sheet (which will tell us information about you such as your age, your education, your marital status and your employment), and a questionnaire that will help us to understand the severity of the ASD (this is referred to as the Child Autism Rating Scale 2nd Edition [CARS-2]).

These forms may be completed in person, over the telephone, or you may wish to mail them back.

Your response to these forms will be kept confidential. Furthermore, responses made on each of the questionnaires completed by your child with ASD will be kept confidential. This is further explained in the final paragraph of Question 17.

Part II – The adolescent sibling:

If you are the brother or sister of a child with ASD, you will be asked to complete 4 questionnaires independent of your parent. You should be able to complete all four of these forms at one interval. It is likely to take less than one hour to complete them.

Your answers will not be shared with your parent. This is further explained in the final paragraph of Question 17.

8. How long will you be in this research study?

Part I – It should take no longer than 20-45 minutes to complete the demographic data sheet and the CARS-2. When you have completed these forms you have completed your participation in the study.

Part II – It should not take more than 1½ hours to complete the four questionnaires. When the questionnaires have been completed, you have completed your participation in this study.

9. How many people are expected to take part in this research study?

It is anticipated that 50 siblings and 50 parents/legal guardians will take part in this study. Approval has been given for 160 siblings and families.

WHAT ARE THE RISKS AND BENEFITS OF THIS STUDY AND WHAT ARE YOUR OPTIONS?

10. What are the possible discomforts and risks from taking part in this research study?

There is a minimal risk of harm to you by participating in this study. Other possible risks to you may include: Sensitive information about your thoughts and/or feelings may be uncomfortable for you to discuss.

Researchers will take appropriate steps to protect any information they collect about you. However, there is a slight risk that information about you could be revealed inappropriately or accidentally. Depending on the nature of the information, such a release could upset or embarrass you. Questions 17-21 in this form discuss what information about you will be collected, used, protected, and shared.

Throughout the study, the researchers will notify you of new information that may become available and might affect your decision to remain in the study.

If you wish to discuss the information above or any discomforts you may experience, please ask questions now or call the PI or contact person listed on the front page of this form.

11a. What are the potential benefits to you for taking part in this research study?

There are no expected benefits to you for taking part in this study.

11b. How could others possibly benefit from this study?

Siblings of individuals with chronic illness or ASD may identify resources that are useful to overcome challenges associated with stressful family environments.

11c. How could the researchers benefit from this study?

In general, presenting research results helps the career of a scientist. Therefore, Laura O. Smith PhD (c), FNP-C, RN may benefit if the results of this study are presented at scientific meetings or in scientific journals.

12. What other choices do you have if you do not want to be in this study?

Your participation is completely voluntary. There is no penalty for not being a research participant.

13a. Can you withdraw from this study?

You are free to withdraw your consent and to stop participating in this study at any time. If you do withdraw your consent, you will not be penalized in any way. If you decide to withdraw your consent to participate in this study for any reason, please contact Laura O. Smith at 727-41-3890.

If you have any questions regarding your rights as a research subject, please call the Institutional Review Board (IRB) office at (352) 273-9600.

13b. If you withdraw, can information about you still be used and/or collected?

If you withdraw from this study, no further information will be collected from you.

13c. Can the Principal Investigator withdraw you from this study?

You may be withdrawn from the study without your consent for the following reasons: A large number of random answers are missing on the questionnaire.

<p>WHAT ARE THE FINANCIAL ISSUES IF YOU PARTICIPATE?</p>

14. If you choose to take part in this research study, will it cost you anything?

No.

15. Will you be paid for taking part in this study?

Each participating sibling will receive a \$20.00 gift card to WalMart.

16. What if you are injured because of the study?

If you are injured as a direct result of this study, the PI, Laura O. Smith, will pay for all reasonable and necessary medical expenses required to treat your injury as long as the injury occurs during the course of the study and results directly from completing the questionnaires in the study.

The sponsor (University of Florida) and the Principal Investigator will determine whether your injury is related to your participation in the study. No additional compensation is offered. The Principal Investigator and others involved in this study may be University of Florida employees. As employees of the University, they are protected under state law, which limits financial recovery for negligence.

Please contact the Principal Investigator listed in question 3 of this form if you experience an injury or have questions about any discomforts that you experience while participating in this study.

17. How will your health information be collected, used, and shared?

If you agree to participate in this study, the Principal Investigator will create, collect, and use private information about you and your health. This information is called protected health information or PHI. In order to do this the Principal Investigator needs your authorization. The following section describes what PHI will be collected, used and shared, how it will be collected, used, and shared, who will collect, use or share it, who will have access to it, how it will be secured, and what your rights are to revoke this authorization.

Your protected health information may be collected, used, and shared with others to determine if you can participate in the study, and then as part of your participation in the study. This information includes your name, your contact information, and your responses on the surveys you complete. Other information includes information such as age, primary language and the mental health information that you provide. This information will be stored in locked filing cabinets in the office of Laura Smith or on computer servers with secure passwords, or encrypted electronic storage devices.

Scores on the questionnaires will be collected individually. A research packet will be given a number and this number will be used on each form instead of your name. No one will know your answers to the questions. However, the identification number on each form can be traced back to the signed consent form.

The information you provide will be kept confidential. The parent will NOT view the response of the adolescent. The adolescent will NOT be given the information the parent provides.

This information will be stored in a locked filing cabinet or on computer servers with secure passwords, or encrypted electronic storage devices.

Some of the information could be included in a “limited data set” to be used for other research purposes. If so, the limited data set will only include information that does not directly identify you. For example, the limited data set cannot include your name, address, telephone number, social security number, photographs, or other codes that link you to the information in the limited data set. If limited data sets are created and used, agreements between the parties creating and receiving the limited data set are required in order to protect your identity and confidentiality and privacy.

18. For what study-related purposes will your protected health information be collected, used, and shared with others?

Your PHI may be collected used and shared with others to make sure you can participate in the research, through your participation in the research, and to evaluate the results of the research study. More specifically, your PHI may be collected, used, and shared with others for the following study-related purpose(s):

To describe and analyze the association of the adolescent sibling’s coping strategies, support networks, psychological well-being and coherence levels to the severity of the ASD.

Once this information is collected, it becomes part of the research record for this study.

19. Who will be allowed to collect, use, and share your protected health information?

Only certain people have the legal right to collect, use and share your research records, and they will protect the privacy and security of these records to the extent the law allows. These people include the:

- The study Principal Investigator, Laura O. Smith, PhD (c), FNP-C, RN and research staff associated with this project.
- Professionals at the University of Florida or Shands Hospital that provide study-related treatment or procedures.
- University of Florida Institutional Review Board (IRB; and IRB is a group of people who are responsible for looking after the rights and welfare of people taking part in research).

20. Once collected or used, who may your protected health information be shared with?

The study findings will be reported as a group without personal identifiers by the researchers. These may be written in professional publications, verbal presentations, and electronic discussion for any persons interested in the topic. Your PHI may be shared with:

- The study sponsor, The University of Florida
- United States and foreign governmental agencies who are responsible for overseeing research, such as the Food and Drug Administration, the Department of Health and Human Services, and the Office of Human Research Protections.
- Government agencies who are responsible for overseeing public health concerns such as the Centers for Disease Control and federal, state, and local health departments.

Otherwise, your research records will not be released without your permission unless required by law or a court order. It is possible that once this information is shared with authorized persons, it could be shared by the persons or agencies who receive it and it would no longer be protected by the federal medical privacy law.

21. If you agree to take part in this research study, how long will your protected health information be used and shared with others?

Your PHI will be used and shared with others until the end of the study.

You are not required to sign this consent and authorization or allow researchers to collect, use, and share your PHI. Your refusal to sign will not affect your treatment, payment, enrollment, or eligibility for any benefits outside this research study. However,

you cannot participate in this research unless you allow the collection, use and sharing of your protected health information by signing this consent and authorization.

You have the right to review and copy your protected health information. However, we can make this available only after the study is finished.

You can revoke your authorization at any time before, during, or after your participation in this study. If you revoke it, no new information will be collected about you. However, information that was already collected may still be used and shared with others if the researchers have relied on it to complete the research. You can revoke your authorization by giving a written request with your signature on it to the Principal Investigator.

SIGNATURES

As an investigator or the investigator's representative, I have explained to the participant the purpose, the procedures, the possible benefits, and the risks of this research study; the alternatives to being in the study; and how the participant's protected health information will be collected, used, and shared with others. privacy will be protected:

Signature of Person Obtaining Consent & Authorization

Date

Consenting Adults. You have been informed about this study's purpose, procedures, possible benefits, and risks; the alternatives to being in the study; and how your privacy will be protected. You have received a copy of this Form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

Adult Consenting for Self. By signing this form, you voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights.

Signature of Adult Consenting for Self

Date

Parent/Adult Legally Representing the Subject. By signing this form, you voluntarily give your permission for the person named below to participate in this study. You are not waiving any legal rights for yourself or the person you are legally representing. After your signature, please print your name and your relationship to the subject.

Consent & Authorization Signature
of Parent/Legal Representative

Date

Print: Name of Legal Representative

Print: Relationship to Participant:

Print: Name of Subject:

Participants Who Cannot Consent But Can Read and/or Understand about the Study. Although legally you cannot "consent" to be in this study, we need to know if you want to take part. If you decide to take part in this study, and your parent or the person legally responsible for you gives permission, you both need to sign. Your signing below means that you agree to take part (assent). The signature of your parent/legal representative above means he or she gives permission (consent) for you to take part.

Assent Signature of Participant

Date

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BIOGRAPHICAL SKETCH

Laura Smith was born in Evergreen Park, Illinois and she is one of six children. Laura began working in 1975 at St. James hospital in Chicago Heights, Illinois as a pharmacy assistant through a Marian Catholic High School education/work partnership. She worked at Foster G. McGaw Loyola Medical Center as a nursing assistant while completing her college degree. She received the Bachelor of Science degree in nursing in 1983 from Loyola University of Chicago. Early in her career as a registered nurse, Laura worked at Rush Presbyterian St. Luke's Medical Center and Mease Hospital.

In 1997, Laura received her Master of Science degree in nursing from the University of South Florida. She holds an active Florida license as an Advanced Registered Nurse Practitioner and is board certified by the American Nurses Credentialing Center. Laura has treated hundreds of patients with acute and chronic medical conditions in several primary care clinical settings.

Laura Smith received her Doctorate of Philosophy degree at the University of Florida. She is a recipient of *Merdinger and Charlotte Liberty* scholarships. Her dissertation, "*The Relationship of Adolescent Sibling Resources to Severity of Autism Spectrum Disorder and Sense of Coherence Levels,*" has opened up new interests in the health of families and young persons. She is a published scholar in the *Journal of Child and Adolescent Psychiatric Nursing*.

Laura has been active in advocating excellence and professionalism for nursing to her colleagues and in her community. She is a long-standing member of the Florida Nurses Association. She has is currently a member of the West Coast Council of Advanced Nurse Practitioners, Southern Nursing Research Society, and the

International Society for Autism Research. She volunteers for the Archdiocese of St. Petersburg and local events for persons with disability.

Laura has been married to Randall J. Smith for more than twenty-five years. They have two sons and a daughter and live on the West coast of Florida. In addition to her love for science, Laura enjoys travel, gardening, and spending time with her friends and family.