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Coping in Parents of Children Diagnosed with Autism Spectrum Disorders

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COPING IN PARENTS OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDERS

by

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This independent study, submitted by Gloria Abaka Ayuck in partial fulfillment of the requirements for the Degree of Master of Science in Nursing from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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Advisor

This independent study meets the standard for appearance, conforms to the style and format requirements of the Graduate School of the University of North Dakota, and is hereby approved.

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Dean of the Graduate School

_____

Date

PERMISSION

Title: Coping in Parents of Children Diagnosed with Autism Spectrum Disorders

Department: Nursing

Degree: Master of Science

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

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Dedicated to

my baby Levi Likane Ngwendson

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His spirit lives on.

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My six year old son with autism who inspired me to work on this project.

ABSTRACT

Coping in parents of autistic children has been studied extensively with emphasis on the effect of long-term disability on families. The increase in the prevalence of autism in the United States increases the likelihood that many families will be managed by mid-level providers including advanced practice nurses (APNs). Parents and siblings of children with ASDs suffer from more stress and mental health issues than families with typically developing children or other disabilities such as Attention Deficit Hyperactivity Disorder (ADHD) and Down syndrome. The purpose of this independent study was to review the literature and practice guidelines examining coping in parents of autistic children in order to identify risks and strategies employed by parents in dealing with the challenges of raising a child with ASDs. The sampled articles used in this study were purposely selected based on their examination of the various aspects of stress and coping in parents of children with ASDs. Results showed that parents used a variety of coping strategies and appeared to learn better coping strategies as their children grew older and they adapted better to their children's routine. Parents with low levels of social support and parents who had children with more severe symptoms had more difficulty in coping. Mothers were more likely than fathers to seek social support and other resources. Social support, support groups and other positive coping strategies such as reframing were used by autistic families. The goal of this capstone project was to design a brochure for APNs. APNs are in a unique position to help identify risks, educate affected families, provide timely services, and make appropriate referrals.

INTRODUCTION

Autism Spectrum Disorders are the fastest growing developmental disorders affecting individuals of all racial, ethnic, and socioeconomic backgrounds. The Center for Disease Control and Prevention (CDC) stated that an average of 1 in 110 children in the United States is diagnosed with some form of autism compared to a prevalence of 1 in 2,500 published in the earliest epidemiological studies of autism in the mid-1960s (CDC, 2010; Rice, 2009; Tanguay, 2010). The Autism Society of America has estimated the lifetime cost of caring for a child with autism to range from $3.5 million to $5 million and a national burden of $90 billion annually (ASA, 2008). Comparatively, the United States Department of Agriculture's Center for Nutrition Policy and Promotion has estimated the overall expenditure on a child from 0-17 years by a husband-wife family in the United States to be $160,410 - $369,360 (Lino, 2010). Though the report from the USDA was not specific to children with ASDs, it gave us an idea how costly it can be to raise any child in the United States without adding the burden of chronic disease in to the mix.

Along with these alarming statistics is the effect that autism has on caregivers and family members. The mental health of parents of children with disability including Autism Spectrum Disorders has been studied extensively and there is a growing body of evidence suggesting that chronic disability has a negative impact on family functioning and that parents of autistic children have poor mental health and high stress levels (Higgins, Bailey & Pearce, 2005; Davis & Carter, 2008). In fact, parenting a child with

autism can be more stressful than being the parent of a child with a chronic illness or other developmental disabilities like Down syndrome (Luther, Canham, & Cureton, 2005).

PURPOSE

The aim of this project is to examine coping strategies employed by parents of autistic children and explore factors that impact the mental health status of these parents through the review of literature and practice guidelines. Autism is a neuro-developmental disability that is not well understood primarily due to the span of the spectrum and the associated symptoms and behaviors. Experiencing a child struggle with autism can be emotionally exhausting for parents and having had the personal experience of going through this emotional roller-coaster as a parent, I had a strong desire to validate my feelings and experiences by determining the strength of the evidence. The goal is to use the information gained to design an informed educational material for Advance Practice Nurses (APNs) to help identify risks, educate affected families, provide timely services, and make appropriate referrals.

SIGNIFICANCE

Autism Spectrum Disorders (ASDs) are identified in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) and include five disorders: 1) autistic disorder, 2) asperger's disorder, 3) childhood disintegrative disorder, 4) rett's disorder and 5) pervasive developmental disorder--not otherwise specified (PDD-NOS). The hallmark characteristics of autistic disorders are atypical development in communication, social interaction and behavior marked by associated impairments that affect multiple areas of functioning including eye to eye gaze, body posture, and speech (APA, 2000).

Individuals with autism have varying levels of severity. Regardless of the severity, caring for a child with autism presents a unique challenge for parents and may represent a constant source of stress and anxiety particularly because autism affects every area of family life.

Advanced Practice Nurses most often provide comprehensive and holistic care to the entire family. As primary care providers, they are in a position to assist in the recognition, diagnosis and management of autistic children. APNs also provide support to families through education and anticipatory guidance. Gaining a better understanding of the mental health of parents with autistic children and their coping mechanisms will enable APNs provide efficient and family-oriented care.

APNs and other primary care providers have the invested role of providing health care services to diverse families. With the rising prevalence of autism, it is highly probable that APNs see a fair amount of families with autistic children in primary care. Holistic care is a mantra that the nursing profession as a whole professes and in no other place does this evoke more meaning than caring for special needs families including autism. APNs are not only instrumental in caring for their medical needs but also sensitive to psychological and emotional issues that underlie these medical problems; they play a vital role in identifying mental health issues, treating them and/or pointing them to the right resources.

Further complicating parental acceptance and ability to effectively manage their child's disease is the various speculations in the popular media over the years about the etiology of autism. One of the controversies that has gained media interest has been the thought that thermarisol, a preservative used in the manufacture of vaccines like Measles

Mumps and Rubella causes autism. As a result, some parents including those without autistic children continue to express concern about the safety of vaccines despite continual effort by the CDC and primary care providers around the country to educate parents so they make informed choices. Some parents have adopted immunization schedules that are different from those published by the CDC. Even though the topic of autism has gained popularity in the mass media, knowledge about its symptoms and management is still growing.

Gaining knowledge of the nature of parental stress and coping mechanisms is a good starting point for APNs in caring for autistic families. There are many sources of stress for parents with autistic children, however dealing with the child's autistic behaviors such as 1) aggression towards self or others, 2) sustained odd play such as spinning objects, 3) persistent fixation on parts of objects, 4) echolalia, 5) mood swings, 6) tantrums, 7) inability to sit still, 8) difficulty making transitions, and 9) inability to accomplish simple tasks can be challenging for parents. The most significance sources of stress for parents raising a child with autism as underscored by Sharpley, Bitsika and Efremidis (1997) are (a) the permanency of the condition, (b) the lack of acceptance of autistic behavior by society and family members, and (c) the low levels of support from health care services and other social services.

Furthermore, depending on the severity of the disease, parents of autistic children are usually the direct caregivers of their children and may have given up their career or full time employment to care for their children. As a result, the physical and mental health of parents with children diagnosed with autism is very critical, so is having a strong social network and significant coping skills as it is very unlikely that these parents

can provide adequate care for their children if they are not healthy themselves (Sawyer, Bittman, La Greca, Crettenden, Harchak, & Martin, 2010).

THEORETICAL FRAMEWORK

Background

The Resiliency Model of Family Stress, Adjustment, and Adaptation is used as a theoretical framework in this project to discuss coping in families with autistic children. The model of stress, adjustment and adaptation evolved from the family stress theory called the ABCX model pioneered by Reuben Hill in 1949 after observing family separation and reunion following the First World War (Friedman, 1998; Robinson, 1997). Hill observed that families responded differently to the same stressors. He identified key factors such as the family's resources and perceptions that influenced the family's ability to cope with stress and explained that it is the balance of these factors that determines their vulnerability to a crisis (Robinson, 1997).

The symbol 'A' is the event or stressor that interacts with 'B' the family's resources, strength or coping mechanisms and work together with 'C' the family's definition of the event to produce 'X' the crisis or non-crisis. In 1983, McCubbin & Patterson built on Hill's model and formed the Double ABCX model and later the Family Adjustment and Adaptation Response (Rice, 2000; McCubbin & Figley, 1983). The Double ABCX is an expansion of Hill's ABCX with the emphasis on the fact that families deal with an accumulation of stressful events rather than just one event at a time. Conversely, the Family Adjustment and Adaptation Response depict the active processes that families engage in the interaction of their demands, capabilities and meanings to

achieve a level of family adjustment or adaptation (Rice, 2000; McCubbin & Figley, 1983).

The Resiliency Model of Family Stress, Adjustment, and Adaptation

The Resiliency Model of Family Stress, Adjustment, and Adaptation developed by McCubbin and McCubbin (as cited in Friedman, 1998) is the product of the earlier theories discussed above albeit more complex. It describes family adjustment and adaptation in the face of stressful life events with an emphasis on resiliency and the strengths and capabilities that influence this process (Friedman, 1998). The assumptions of the resiliency model were discussed earlier prior to the full development of the model by McCubbin and Thompson (1987). They stated that: (1) hardships and changes are a natural and predictable aspect of family life that families face over a life cycle; (2) in the face of these changes or transitions, families develop basic strengths and capabilities designed to promote growth and development of family members and the family unit and to protect them from major disruptions during transitions; (3) families develop basic and unique strengths and capabilities designed to protect the family from unexpected stressors and strains and to promote the family's adaptation following a crisis or change; and (4) families contribute to and benefit from the network of relationships and resources in the community, especially during periods of stress and crisis (McCubbin & Thompson, 1987).

This model describes two phases; the adjustment phase and the adaptation phase (See Appendix A). McCubbin and Thompson (1987) restated that these phases both describe families at two related but discernible stages in their response to life changes. The adjustment phase shows how the family responds to minor changes or events that do

not present a major change in the family unit such as an acute illness with complete recovery. Family adjustment is determined by the stressor event (e.g. a diagnosis) interacting with the family vulnerability due to life changes and the pile up of demands (e.g. marital conflict, divorce). These variables act together with the family type, the established patterns of functioning, family's appraisal, resources, problem-solving and coping mechanism to determine how the family responds, resulting either in a bonadjustment or maladjustment. McCubbin and McCubbin (as cited in Friedman, 1998) defined bonadjustment as a state where the individual family members are able to achieve stability and reach their maximum potential such that both the individual and family unit can function adequately in the community. On the other hand, maladjustment is considered a crisis situation and occurs when the individual or family unit is unable to adapt properly to their environment thus creating a crisis situation (Rice, 2000; Friedman, 1998; McCubbin & Thompson, 1987).

The adaptation phase results from a crisis situation, conceptualized in this model as a continuous state of disruption or disorganization in the family's social system. The family's response to a crisis situation in the adaptation phase is determined by their 'pile up demands', and the strength and capabilities of the family unit. The family strengths and capabilities include newly established patterns of functioning, the family's appraisal and new world view, resources within the individual, family and the community and the family's existing and newly developed problem solving and coping strategies (Friedman, 1998). Adaptation results either in successful adaptation depicted in the model as bonadaptation which means that the family is able to achieve a sense of coherence and stability when faced with a crisis; or unsuccessful adaptation *aka* maladaptation which is

considered in the model as a crisis situation where family function is chaotic and the growth and development of family members is stagnant. In this state, the family's overall sense of trust, order, well-being, and coherence is very low (Robinson, 1997).

DEFINITIONS

Coping

In order to better appreciate how parents of autistic children cope with the challenges of raising their children, it is important to understand the concept of coping. Even though there has been considerable variation in the conceptual and operational definition of coping, it has been used with reference to how individuals deal with problems (Gray, 2006). Lazarus and Folkman (1984) have studied stress management and coping extensively and their publications have been referenced by many authors as benchmark studies in this area of research. They defined coping as a continuous process of "changing cognitive and behavioral efforts to manage [adapt to] specific external and /or internal demands [stressors] that are appraised as taxing [challenging] or exceeding the resources of the person" (Lazarus & Folkman, 1984, pg. 141).

Lazarus and Folkman (1984) also described two types of coping strategies: problem focused and emotion focused coping strategies. They claimed that the goal of problem-focused coping is to alter or manage the problem causing the distress. As a result, the individual makes an effort to define the problem; identify personal strengths and weaknesses; generate alternative solutions; weigh the cost and benefits of various actions; change what is changeable in self or the environment; and learn a new skill if necessary. On the other hand, they also believed the goal of emotion focused coping is to decrease emotional distress; hence the individual will employ approaches like distancing;

avoiding; selective attention; blaming; wishful thinking; minimizing; and venting emotions. Lazarus and Folkman (1984) maintained that everyone uses both forms of coping when dealing with stressful events; problem-focused when the situation is appraised as changeable, emotion-focused when events are not changeable.

Social Support

Cobb (1976) defined social support as the exchange of caring information at the interpersonal level. According to Cobb, social support has three components; 1) emotional support that makes the recipients feel that they are cared for and loved, 2) esteem support which leads the receiver to believe that they are esteemed and valued, and 3) network support makes the family members believe that they belong to a network of communication and mutual obligation (Cobb, 1976; Friedman, 1998).

METHOD

This topic "coping in parents of children diagnosed with autistic spectrum disorders" stemmed from personal experience and curiosity. Initially, the intention was to look at the mental health of parents of children with autism as this author was raising a preschooler with autism and going through psychological challenges at the time that this topic was formulated. The initial search for articles started with the use of the term autism on data bases like PUB MED and SCOPUS through the Harley French Medical School library of the University of North Dakota which yielded about 20,000 articles. The goal was to get a bird's eye view of what has been published on the subject in order to help formulate a topic. Next, the term autism was paired with terms like statistics, resources, mental health, parenting stress and coping in order to be educated on the subject. Most of

these terms yielded over 200 articles on data bases like PUB MED, SCOPUS, and CINAHL.

Also, this author searched the Harley French library resources by entering the key term autism to find specialized journals and found about ten journals like *Autism, Autism Spectrum Disorders: Identification, Education, and Treatment, Focus on Autism and Other Developmental Disabilities, Focus on Autistic Behavior, Journal of Autism and Developmental Disorders.* Within these journals, the same search terms were used, for instance, an advanced search of autism, families and mental health together in all fields yielded 1039 articles published from January 1990 to May 2010 in the journal - *Autism.* Several of these articles were very informative and it would be beyond the scope of this study to go through all of them. As a result, this author was unable to conduct an exhaustive appraisal of all the relevant articles. Therefore, there is a potential for bias as there may have been some information missed in the process.

When this topic was finally fine-tuned, the author entered the topic "coping in parents of children diagnosed with autistic spectrum disorder" on SCOPUS and yielded no results. It was the same on PUBMED except it generated about 60 articles that had key terms but not the entire topic as it was written. It was then that the author decided to move forward with this topic as written above with the consent and recommendation of the student's advisor. The articles that were used in this review of literature were selected based on their examination of the various aspects of stress and coping in parents of children with autism. In addition, there was a purposive selection of some relevant articles that were referenced by other authors in their literature review.

The ultimate goal of this project was to design an educational material for providers that will include pertinent information such as stress and coping styles in parents of autistic children and some online resources for these families. Brochures usually discuss autism as a diagnosis and neglect to address the people and the faces behind the diagnosis. This brochure will provide valuable information and knowledge harvested from a variety of sources including peer reviewed journals accessible to providers.

LITERATURE REVIEW

The Nature of the Problem

Parents of autistic children are challenged on so many levels because autism affects many aspects of family life as portrayed in a qualitative study by Phelps, Hodgson, McCammon and Lamson (2009). Phelps et al. examined the multidimensional implications of having a child with autism on family life and overall functioning. The challenges reported by these caregivers in Phelps et al.'s study include a strain on caregivers' romantic relationships, providing equal attention to all of their children's accomplishments, jealousy between siblings, and psychological well-being for typically developing siblings. Socially, the caregivers felt that the lack of understanding surrounding this disorder led to frustrating social interactions with those without a child with autism. Caregivers verbalized frustration with the school system; many caregivers have chosen to home school, utilize private schools, and hire additional support. Caregivers also were concerned by the lack of patience from medical professionals, the lengthy time necessary to obtain diagnosis, and deficient laws for those who abuse children with autism. These concerns were shared by parents/caregivers in a survey

conducted by Higgins, Bailey and Pearce (2005), in which 22 percent of caregivers stated that family, friends, teachers and the community did not understand the behavioral characteristics of children with ASD. These caregivers acknowledged a high level of stress and the negative effect on family life, with 41percent reporting some form of physical, emotional, financial, or relationship stress. Simple things such as the family going out to eat together or going out on a normal, spontaneous outing were expressed as difficult to accomplish by these caregivers because of the child with ASD.

These same concerns were echoed by mothers in a qualitative study conducted by Bourke-Taylor, Howie and Law (2010). Researchers interviewed mothers of children with neurodevelopmental disabilities namely cerebral palsy and autism to examine the lived experience of caring for a child with a disability. All participants acknowledged that many aspects of caring for their children were mentally and emotionally challenging. Some of the challenging areas included learning about the meaning of the diagnosis, the extent of disability and new tasks. Also, being constantly involved in either direct or indirect care giving; child's routine; therapy interventions and medical assistance was another area that caused strain. Caregivers also mentioned the child's aggressive behavior; an absent or unhelpful spouse; anxiety and guilt about siblings coping abilities; financial problems; unavailability or difficulty navigating the services; dealing with the stigma of the disability and social isolation (Bourke-Taylor, Howie & Law, 2010).

Several studies have also demonstrated that parents, particularly the mothers of children with ASD, report higher affective symptoms such as depression and anxiety than parents of children with other or no developmental disabilities (Duarte, Bordin, Yazigi & Mooney, 2005; Davis & Carter, 2008; Lee, Harrington, Louie, & Newschaffer, 2008;

Dabrowska & Pisula, 2010; Sawyer, et al., 2010; Bourke-Taylor, Howie & Law, 2010). Coping strategies in families with children diagnosed with ASD differ from families with children without ASD. Sivberg (2002) studied strain on the family system and compared the coping behaviors of parents of children with ASD to those of parents with non-ASD children. Predictably, there was a much higher level of strain on the family system for families with a child who has an autistic spectrum disorder and a negative relationship was noted between the level of strain on the family system and the level of coping. Sivberg (2002) found that the parents with a child with ASD scored higher in coping behaviors of distancing and escape, a behavior that construes a mental or physical avoidance from a stressful situation. Parents in the control group scored higher in use of self-control, social support, and problem solving which are constructive methods of coping. Though this study was conducted in a single county in Sweden, it was fairly representative of families with ASD and Sivberg used a fairly comparative group of parents for both the experimental and control group.

In addition, Sawyer et al. (2010) found that there was a positive relationship between the level of time pressure and the level of mental health issues experienced by mothers and also that mothers who reported more social support reported fewer mental health problems. Also of interest is the finding in this study that mothers spent an average of 6 hours a day caring for their child with autism. On the other hand, the effect of autism is not always negative as underlined by Phelps et al (2009). The caregivers in Phelps et al.'s study reported gains in knowledge and virtues like patience, insight, motivation, and selflessness. The caregivers also agreed that having a child with autism enabled them to

meet new people who shared in their struggles and strengthened bonds between family members.

Coping Strategies in Families with Autistic Children

Coping in families with autistic children has been broadly studied and there is a large body of evidence examining how families cope with autism at various stages of development across the lifespan and the coping patterns utilized by parents to cope with autism. Albeit there are many more studies on the mothers and siblings of autistic children than there are on fathers of autistic children. As echoed in many studies, the mother is most often the primary caregiver reasonably justifying the imbalance depicted by research data. In addition, Bourke-Taylor, Howie, and Law (2010) stated that in up to 98 percent of cases mothers are more knowledgeable about the health and needs of a child with disability. A major concern articulated by parents is coping in non-disabled siblings. Macks and Reeve (2007) argued that the presence of a child with autism appears to enhance the psychosocial and emotional development of non-disabled siblings, when demographic risk factors are limited. However, as demographic risk factors increase the presence of a child with autism appears to have an increasingly unfavorable impact on the non-disabled sibling. Demographic risk factors are things like race, religion, marital status, gender of the child with autism, and gender of non-disabled child.

Coping strategies employed by parents of children with ASD appear to evolve over time and may differ with the child's stage of development. Gray (2006) determined, through a 10 year longitudinal study examining coping in parents of children with autism, that coping strategies changed over time. Using in-depth interview and participant observation, 35 parents were interviewed at the initial study; 28 of which participated in

the follow-up study 8-10years later. At the follow up study, researcher noted a general shift form problem-focused coping to emotion focused; fewer parents coped through reliance on service providers, family support, social withdrawal and individualism as indicated in the initial study and more parents cope through religious faith and appreciation of their child's good qualities. Gray argued that this may reflect the changing problem of their children as most children had improved over time exhibiting less disruptive behavior and parents are adapted to the child's routine such that they experience less distress relating to their child's disorder. Even though the children were still significantly disabled, Gray explained that parents seemed to have come to terms with the fact that considerable recovery is less feasible as previously hoped.

However, besides the limitation in sample size in Gray's study, it is worth mentioning that there is an inherent bias in sample selection by nature of the type of study being that it was a qualitative study. Also, the fact that participants were recruited from a specific region and treatment center may limit generalization. Gray (2006) was not able to determine whether it was the changing nature of the child's problem or the limited access to appropriate services that had the most influence in the change in parental coping strategies. This evidence should be compared with similar studies replicated in other geographic areas and treatment centers and larger sample sizes with increased demographic variables to enable generalization.

On the other hand, Hastings, Kovshoff, Brown, Ward, Espinosa, and Remington (2005) studied different associations including how the age of a child influences parental choice of coping strategy and found that there was no reliable evidence that the child's age and thus the stage in the family life-cycle was influential in parents' approaches to

coping. Though stress and family adaptation appear to vary considerably as the child develops through infancy, childhood, adolescence and into adulthood, Hastings et al purported that it is the parents' experience of stress that changes over time.

Coping can be influenced by demographic variables. Twoy, Connolly and Novak (2007) used the Family Crisis Oriented Personal Evaluation Scales (F-COPESs) instrument to examine coping strategies used by of parents of children with autism aged 12 years and under. The main goal was to identify the level of family adaptation and to determine if there was a difference in F-COPES scores based on family demographics. Though the F-COPES instrument lacks qualitative measurement, it is a very reliable tool with a Cronbach's alpha reliability of 0.86 and a test–retest reliability of 0.81. Researchers found among other things that the overall level of adaptation was similar to the norm scores of the F-COPES with males scoring slightly higher than females in the coping scale. They identified strategies that were specific to some ethnic groups like Asian Americans used reframing to define the stressor in a more positive way such as viewing it as a part of life not a source of discouragement. Caucasians scored higher in passive appraisal while Asian Americans revealed a higher coping score for reframing. The authors believed that this response may have been influenced by the core values of Eastern religion. About 50% of the people surveyed in this study believed in God and found spiritual support as a coping strategy. However, Non-English speakers scored higher on spiritual support, while English speakers scored higher in passive appraisals. Also, spirituality served as a key coping tool for many caregivers in redefining and strengthening their values through this parenting process in the study conducted by

Phelps et al. (2009). Other variables like education, income, marital status, and relocation of residence were not examined due to insufficient statistical power.

Having a child with autism can limit parental involvement in social activities and interaction with families and friends. Lee et al. (2008) stated that families of children with autism reported a greater level of child caring burden, less frequent attendance of religious services, a greater likelihood to quit a job, less participation in activities/events, and less involvement in community services, compared to families of children with ADD/ADHD or unaffected children. However, as explained by Altiere and Von Kluge (2009), social support is an integral part of coping for these families and even more significant for mothers of autistic children because studies have shown that mothers who perceive social support to be accessible report fewer stress related somatic symptoms. Social support is a positive coping strategy that has been successfully used by parents of children diagnosed with autism. Twoy, Connolly and Novak (2007) demonstrated that parents identified the use of social support systems within the family's social network such as close friends, extended families and the use of external resources such as families with similar problems community resources for families with autism to share their concern, obtain information, and seek advice. They also identified some maladaptive coping strategies used by parents in this study such as avoidance behaviors like watching TV, passive appraisal such as resigning to fate with the belief that they do not have the power to alter the outcome their child's disorder. Social support has also been shown to decrease marital conflicts; Rivers and Stoneman (2003) used family systems theory to demonstrate that social support could buffer the negative effects of marital stress on the sibling relationship.

Support groups have been used by individuals with chronic illnesses and disabilities as a resource. Mandell and Salzer (2007) identified factors associated with support group participation among families of children with autism. The aim of the study was to document the extent to which families of children with autism use support groups, and identify factors associated with support group participation, such as basic family demographics and clinical characteristics of the child. Survey data were collected from June through September 2004 using a snowball sampling approach. Participants were recruited by mailing to caregivers of individuals with autism and a total of 1005 subjects were included in this survey. Findings from this study suggest that two-thirds of families of children with autism have participated in autism-specific support groups and more than half are currently participating. Support group participants were more likely be parents of older children, they were more likely to have children who engaged in self-injurious behaviors, had sleep problems and had severe language deficits. One major limitation of the study was the inability to validate autism diagnoses and reporting of related symptoms.

Nevertheless, not all types of families seek social support. Also, mothers and fathers seem to differ on their perception of social support as a coping mechanism. Though it might seem unfair to compare the coping mechanisms of mothers and fathers given that there are more studies on mothers than fathers, it is worth examining how gender affects parental perception of coping mechanisms in parents with autistic children. Altiere and Von Kluge (2009) compared mothers' and fathers' reports of family functioning, coping strategies and satisfaction with the family's level of functioning in families of children with autism. Coping was measured by perceived social support while

family functioning was measured by cohesion and adaptability. Cohesion is defined in this study as "the emotional bonding that family members have toward one another" (Altiere & Von Kluge, 2009, p. 84). The levels of cohesion are: enmeshed, the highest level of cohesion, followed by connected, separated and disengagement in respective order. Highly enmeshed parents are overprotective of their children while disengaged parents are under-involved. Experts believe that a family that falls between the two extremes may be better suited for raising a child with autism. Adaptability is a measure of "the family's ability to change in response to a stressful situation" (Altiere & Von Kluge, 2009, p. 84). Adaptability is also measured on a scale from rigid to chaotic with structured and flexible falling in between the two extremes. A rigid family resists change while a chaotic family changes unpredictably. Children with autism need a highly structured environment but there has to be some flexibility and ability to adapt to change.

Altiere and Von Kluge (2009) hypothesized that mothers would be more likely to rate family coping mechanisms, cohesiveness and adaptability higher than fathers; perceive more social support and be more satisfied with the level of family functioning than fathers. Overall, they had expected that a moderate level of family cohesion and adaptability will relate to higher levels of perceived social support and positive coping behaviors. Altiere and Von Kluge used three different scales namely the Family Crisis Oriented Personal Evaluation Scales (FCOPES), the Family Adaptability and Cohesion Evaluation Scales – III (FACES-III) and the Perceived Social Support from Family and from Friends (PSS-Fa and PSS-Fr) to measure family's coping with stress, family member's perceived and desired family cohesiveness and ability to adapt to change and perceived social support from family and friends respectively. Interestingly, they did not

find a significant difference in the couple's coping scores; both parents agreed in their ratings of cohesion, adaptability and satisfaction with the level of family functioning and family coping mechanism. However, mothers were more likely to believe that their family seeks social support in times of crisis. In addition, as predicted, families that were more enmeshed and connected were more likely to use social support as a coping mechanism than disengaged families.

It seems reasonable to expect that mothers and fathers will report different coping strategies given the variation in gender roles and how differently they respond to stress. The question whether parental gender impacts parental coping style was tackled by Hastings et al. (2005). Hastings et al. studied different associations including how parental gender influences choice of coping strategy. They studied two groups of parents; parents of preschoolers, ages 28 to 45 months and parents of school-age children ages 8–17 years. They used the Brief COPE, a 28 item scale that outlines coping statements for respondents to select the strategy they have been using. The coping dimensions measured were active avoidance, problem-focused, positive, and interestingly religious and denial were classified in the same category. Substance use, behavioral disengagement, self-blame, and venting of emotions showed active avoidance planning. Active coping and seeking instrumental social support demonstrated problem-focused. The use of humor and positive reframing showed positive coping and finally religious beliefs, prayer or meditation, and denial were classified as religious/denial. Findings suggested that mothers and fathers may adopt different coping approaches. Mothers reported more frequent use of active avoidance and problem focused coping strategies than fathers. As explained by Hastings et al., these results reinforced the evidence that mothers experience

more stress than fathers of children with autism and therefore, seek a variety of coping methods to deal with their stress. They did not identify any effects or interaction for positive coping and religious/denial coping scales. Hastings et al. (2005) concluded that various contextual variables may have an impact on the approaches parents adopt to cope with raising a child with autism.

DISCUSSION

Interpretation

Despite the fact that early intervention and behavior therapy has improved the quality of life of children with autism, coping with autism is a life-long struggle in most families with a child diagnosed with autism. Families have to learn how to deal with things that are beyond their control such as the child's behavior pattern and mental retardation. What makes coping with autism intriguing is the permanence of the diagnosis, oddity of the symptoms, complexity of the disorder, span of the spectrum, and uncertainties relating to disease identification and treatment outcomes. Also, depending on the severity of the disorder, it may be hard for parents to deal with aggressive behaviors that their child may inflict on self or others, parents may be direct caregivers and may not be able to pursue interests out of the home. It is an established fact that parenting a child with ASD is more stressful than parenting a typically developing child or child with other disabilities. Many researchers have concluded that the severity of the child's impairment and behavior problems are predictors of parental stress, in other words the more behavior, social and communication problem a child has, the more likely the parents are stressed (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Dabrowska & Pisula, 2010).

There are a variety of instruments used in measuring coping in families which includes: the Family Crisis Oriented Personal Evaluation Scales (F-COPESs), the Brief COPE, Family Adaptability and Cohesion Evaluation Scales – III (FACES-III), the Perceived Social Support from Family (PSS-Fa) and the Perceived Social Support from Friends (PSS-Fr). Though these instruments all have limitations, they are reliable and have robust research backing their use in studies. In several studies, these instruments were used in combination to measure different aspects of family life.

Autism affects every aspect of family life with mothers of children with autism showing increased affective symptoms and increased levels of stress. Parental coping changes with time and stage of development of the child with autism. Earlier in the development of children with autism, parents have shown to be more emotional but as the child grows older, the parent's coping abilities improve and become more problem focused. This is reasonable due to the fact that parents become more educated about their child's disability and have adapted more to the child's routine. Also another reason which was not necessarily illustrated in the articles researched in this project would be the assumption that parents grieve the loss of a perfect child when they have a child with a disability like autism. As they learn more about the disability, their expectation of the outcomes of treatments decreases as they learn to understand the goal is not to get the child to a perfect functioning child but to help the child attain their maximum potential. Thus, even if they have not attained acceptance, using Kübler-Ross Stages (1975) of grief as an analogy, they are usually further in the process of grieving than the initial shock, anger and denial. In addition, there are some positives to having a child with autism; parents of autistic children indicated in some studies that they gained resilience, patience,

selflessness; they have learned to cherish little things, be more grateful, and autism has strengthen the bond between some families. Researchers however, made it clear that it is not the child's age that influences parental choice of coping strategy; it is the parent's experience with stress that changes over time. In other words parents gained better coping skills with time, not the child outgrowing their autistic behaviors, as most children with autism continue to face different challenges with every stage of development despite the severity.

Coping can be influenced by demographic factors such as spirituality, race or ethnic group. Parents with autistic children identified spirituality as a major positive coping strategy. Conversely, in a study by Twoy et al. (2007), people of Asian origin were shown to use positive coping strategies like reframing while Caucasians scored higher in passive appraisal. There are gender differences in the choice of coping strategies; women experience more stress thus tend to use a variety of coping methods as discussed earlier. However, not all demographic variables were considered in this study. As a result, it is very important when considering demographic factors to be careful to not consider them in isolation; they should keep in mind that individual families respond to stress in different ways; depending on the context, resources available they may cope in different ways regardless that may defy our knowledge of certain ethnic or racial groups. In the *Resiliency Model of Family Stress, Adjustment, and Adaptation,* McCubbin and McCubbin (as cited in Friedman 1998) claimed that the family's adjustment to a stressor is determined by the stressor interacting with other key factors affecting the family such as the family type, resources, their vulnerability due to other life changes and their problem solving abilities. Using one type of family as an example, we can illustrate the

fact that demographic factors must be used in context. A family that places more emphasis on time and routine is described by McCubbin and Thompson (1987) as a rhythmic family. When a major change like a divorce occurs in a rhythmic family, the family's response will depend on not just their race, or ethnic group, but also on other factors like their ability to seek social support, their experience past crisis, the presence of concurrent issues and available resources. In addition, autistic children adhere religiously to routines; they react negatively when their routine is changed.

Despite the fact that families with autistic children tend to be too busy to participate in social activities, social support is fundamental to coping in these families as shown in many studies. However, families with autistic children equally believe that the community is not adequately educated on autism and how to interact with autistic children which makes it hard for families when in public places. We also belong to an age where people can communicate with others without leaving their house through online forums and other media. Mandell and Salzer (2007) found that a large proportion of families with autistic children belong to and are currently participating in support groups.

A major source of stress for parents is access to services. Many services for autistic children are not covered by insurance leaving parents with difficult choices which sometimes may mean selling their homes and moving to resource rich areas. For instance in North Dakota, there is only one psychologist that provides Applied Behavior Analysis (ABA) consulting services and no providers that offer ABA therapy compared to several consultants and ABA therapists in other states such as Minnesota. Parents that require these services have to make difficult decisions to move to resource-rich areas. ABA is

behavior therapy based on operant conditioning that is used in the treatment for autism. Moreover, federal assistance programs are implemented differently in every state, the eligibility and income criteria differ which may eliminate children with autism and deny them access to services. Also, it typically takes long to receive a diagnosis of autism. This coupled with the long wait times to get into services like Applied Behavior Analysis can be frustrating for parents which can be a constant source of concern.

There is an urgent need for comprehensive and affordable health coverage for children with autism and the availability of services in our communities. The second report of the committee on the quality of health care in America published by the Institute of Medicine (2001) identified strategies for the improvement in the quality of healthcare in the United States of America. In this report, is the recommendation requiring all healthcare organizations public or private to provide health care that is safe, effective, patient centered, timely, efficient and equitable which is very applicable for families with autistic children (IOM, 2001).

Recommendations for further studies include more studies on fathers of autistic children. More studies have been conducted on the mothers of children with ASD than fathers and even in studies that fathers are including in mothers significantly outweigh the fathers in the number of participants. Overall, studies of autistic families have very small sample sizes which might reflect the fact that these families are often busy caring for their children such that they are unable to invest time in studies that maybe time-intensive.

Outcome

The deliverable product is a brochure that communicates the challenges that parents of children with ASD endure how caregivers cope and draws attention to the people behind the faces of autism. It is an easy read but also provides information that is current from peer reviewed journals without bogging the reader with deep statistical data. It also delves into what providers can do to help meet the needs of these families. The deliverable product is attached as Appendix C.

The brochure was submitted to a group of five physicians and one physician assistant at the local clinic where the student is currently completing her clinical rotation. All the physicians and the physician assistant responded. They all liked the brochure and felt that it communicated what it intended to communicate. However, they added suggestions such as including some statistics for autism to make the case more powerful, and adding resources where providers could go for information. Also, they thought the language in some places was a little too technical for a brochure; as a result there were a few sentences that were rephrased to help clarity. One provider suggested that the following sentence for instance be broken down into three short straight forward statements: *Factors that increase risk for mental health problems are the gender and age of parents, severity of child's behavior symptoms, availability of social support, and parental psychological characteristics such as coping style*. Due to the limitation of space and possible copyright issues, Holly Robinson Peete's picture and comment that featured on the copy that was submitted to the providers were taken out. The reason for using the picture was to convey a more powerful message by a celebrity figure who is the

mother of an autistic child. A major limitation was the fact that this student was unable to present the brochure to advance practice nurses even though it was intended for them.

Implications to Nursing

Since the early 1990s, the number of persons receiving services for ASDs has increased substantially which implies that providers including advance practice nurses (APNs) have been and will be seeing more clients and their families (CDC, 2010; Myers & Johnson, 2007). As a result, it is imperative for providers to arm themselves with adequate knowledge to meet the needs of families with ASDs. APNs like other healthcare providers involved the care of autistic children play the important role of identifying signs of ASDs, referring for diagnostic evaluation, educating caregivers and providing ongoing care and support of families with autistic children. Besides the routine preventive care and treatment of acute illnesses, APNs understand that the primary goals of treatment as outlined by the American Academy of Pediatrics are:

> "to minimize the core features and associated deficits of autism spectrum disorders, maximize functional independence and quality of life, and alleviate family distress by facilitating development and learning and by promoting socialization, reducing maladaptive behaviors and educating and supporting families" (Myers & Johnson, 2007, pg. 1162-1163).

In addition, we now know that parents and the family unit play a significant role in the functional development of a child with ASDs. There is also good research supporting the link between autism and poor mental health in parents and siblings of autistic children with mothers showing more affective symptoms than the rest of the

family. As a result the care and management of a child with ASDs should move beyond the child and extend to the entire family.

It also important to assess caregivers for increased psychosocial strain, and treating or referring them for counseling when appropriate. Is is also important to tailor treatment goals to the unique family dynamics because the spectrum is wide and research has shown that parents of autistic children with severe symptoms are at greater risks for maladaptive coping and mental health issues. Providers have to be sensitive to the divergent experiences and needs of caregivers and make an effort to incorporate family/caregivers into program planning. Practitioners who work with families of children with autism need to be aware of the coping strategies that parents use to deal with the demands of parenting and how that varies within the family unit. APNs should not ignore the basics especially in newly diagnosed families; educating them about ASDs, providing anticipatory guidance, directing them to appropriate resources, providing emotional support even if it is just by listening, and empowering and respecting them as cotherapists and advocates of their children (Myers & Johnson, 2007).

APNs must be aware of the tools and resources that caregivers have access to help them cope such as social support. Social supports extends from the spouse, siblings, extended families and friends to neighbors and community resources such as religious organizations like churches and institutions like respite agencies, support groups for siblings and families with ASDs. A huge part of stress stems from the lack of resources, hence assisting them in taking advantage of federal and state programs like early intervention, special education, Medicaid, in-home or center-based programs and other financial subsidies can help reduce stress.

Due to the complex nature of this disorder, providers have to remain abreast with research in order to keep their practice current. Even more essential is the fact that each states has different legislations, state-administered programs and available services, different eligibility criteria, providers need to be informed so as to help families navigate the arena. There are several resources within the states that could help provider gain knowledge of the available resources such as the department of health and human services, the state mental health or developmental disability organizations, the local parent advocacy groups or autism organizations, and the school district special education programs providers.

CONCLUSION

Current research studies have demonstrated that parents, particularly mothers of children with ASD are at significant risk for mental health distress. The levels of reported distress are associated with high levels of child behavior problems and low levels of informal support within the family and coping strategies. Parents of autistic children use a variety of coping strategies to deal with the challenges of raising their children. Several factors have been identified as increasing stress in these families; however appropriate interventions can promote psychological well-being in parents of autistic children and help adopt a more positive coping strategy. APNs as well as other primary care providers have the invested role of identifying risks, conducting appropriate assessments and diagnoses, and making proper referrals and providing education to families. ASDs are a lifelong condition and as Myers and Johnson (2007) explained children with ASD may lose certain behavioral characteristic as they grow older and treatment outcomes may vary with the individual but all individuals with autism spectrum disorders regardless of

the severity will continue to struggle with issues related to employment, social interactions, mental health and independent living. This implies that they will continue to need a good social support network and as it turns out, their family is the first line of support they need; we as providers need to foster that relationship and work towards future goals.

APPENDIX A

Figure 1: *The Resiliency Model of Family Stress, Adjustment, and Adaptation Source; Freidman, 1998. pg. 442*

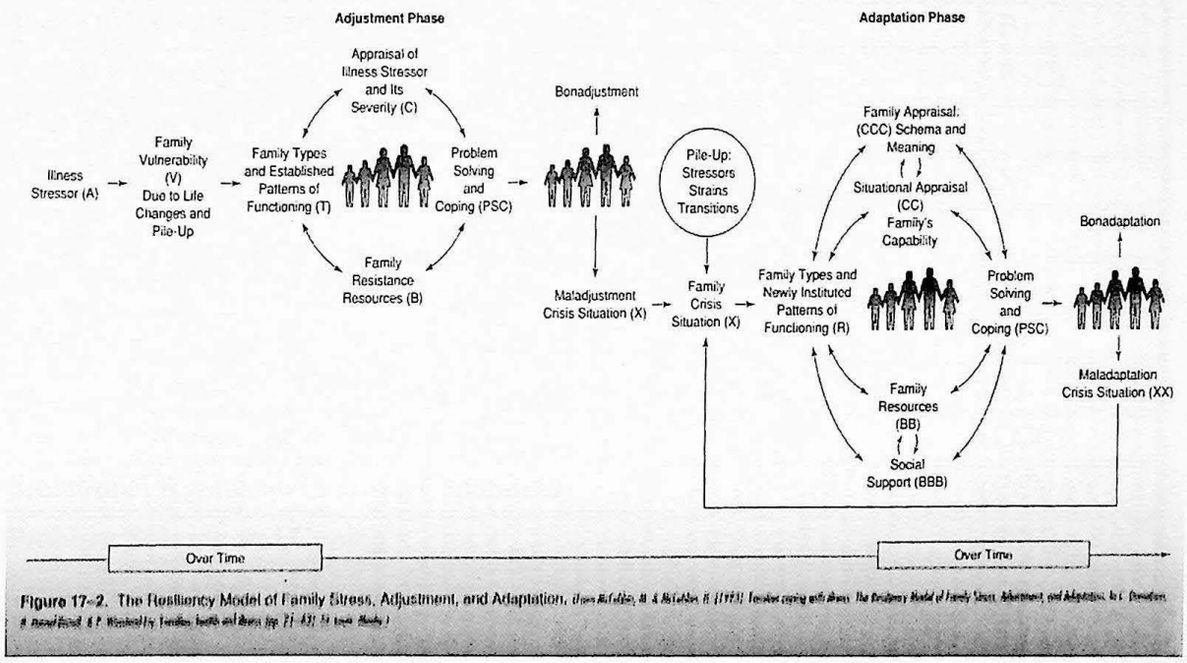

Figure 17–2. The Resiliency Model of Family Stress, Adjustment, and Adaptation.

APPENDIX B

Table 1: Key to the Resiliency Model of Family Stress, Adjustment, and Adaptation

Adjustment Phase	
Illness Stressors:	(A)
Family Vulnerability Due to Life Changes and Pileups	(V)
Family Types and Established Patterns of Functioning	(T)
Appraisal of Illness Stressor and Its Severity	(C)
Family Resistance Resources	(B)
Problem Solving and Coping	(PSC)
Bonadjustment	
Maladjustment Crisis Situation	(X)
Adaptation Phase	
Pileup: Stressors, Strains, and Transitions	(AA)
Family Crisis Situation	(X)
Family Types and Newly Instituted Patterns of Functioning	(R)
Family Appraisal, Schema and Meaning	(CCC)
Situational Appraisal, Family's Capabilities	(CC)
Problem Solving and Coping	(PSC)
Family Resources	(BB)
Social Support.	(BBB)
Bonadaptation	
Maladaptation Crisis Situation	(XX)

Information extracted from Friedman, 1998, pg. 442

COPING IN PARENTS WITH AUTISTIC CHILDREN

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APPENDIX C

WHAT YOU NEED TO KNOW

- ❑ Autism is a life-long neuro-developmental disorder.
- ❑ 1in 110 children have autism in the U.S.
- ❑ Children with autism need a highly structured environment., though there has to be some flexibility from their caregivers and ability to adapt to change.
- ❑ Many families care for their autistic children at home.
- ❑ Autistic children usually require more attention, and effort because of their challenging behaviors.
- ❑ Mothers report an average of 6 h per day caring for their autistic child.
- ❑ The public and providers lack understanding of the disorder and potential effects on the caregiver's health.
- ❑ Mothers of autistic children report a high level of stress and affective symptoms like depression.
- ❑ Mothers with more time pressures also report more psychological symptoms.
- ❑ The more behavior problems a child has the more stress the family experiences.
- ❑ Mothers and younger parents report more stress than fathers and older parents.
- ❑ Families with more social support report less stress and mental illness.
- ❑ Parents with healthy coping habits report less stress.
- ❑ Caregivers are unlikely to provide effective care for their children if their own health has been compromised by their children's disabilities.

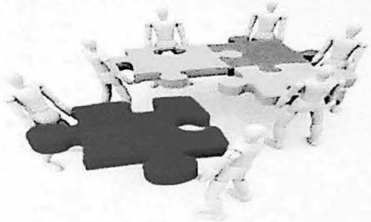
HOW DO PARENTS COPE ?

- ❑ Social support is vital to coping for these families.
- ❑ Studies have shown that mothers of autistic children who perceive social support to be accessible report fewer stress related psycho-somatic symptoms.
- ❑ Just like other chronic illnesses, support groups are a resource for families with autistic children.
- ❑ Mothers experience more stress than fathers of children with autism and therefore seek a variety of coping methods to deal with their stress.
- ❑ Parents learn better coping skills as they learn more about autism and how to adapt to their child's environment.
- ❑ Parents gain patience, insight, motivation, and selflessness while parenting their child with autism.

SAMPLED RESOURCES

- Center for Disease Control- www.CDC.gov
- Autism Society of America- www.autism-society.org
- Autism Speaks- www.autismspeaks.org
- Autism Link- www.autismlink.com
- Foundation for Autistic Childhood Education and Support (FACES) - www.facesforkids.org
- Family Village-Autism Resources http://www.familyvillage.wisc.edu/lib_autm.htm

IMPLICATIONS TO NURSING



- ❑ Assess caregivers for increases in psychosocial strain.
- ❑ Be sensitive to their divergent experiences.
- ❑ Tailor treatment goals to their unique family dynamics.
- ❑ Be educated on the characteristics of ASDs and available resources for referrals in your area.
- ❑ Incorporate family/caregivers into program planning and empower them as advocates.
- ❑ Assist caregivers in identifying resources to cope with the psychological, familial, social or economic challenges.
- ❑ Guide caregivers towards empirically supported interventions.
- ❑ Understand that the goal of treatment is to minimize the core features and associated deficits of ASDs, maximize functional independence and quality of life, and alleviate family distress.

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REFERENCES

Altiere, M.J. & Von Kluge, S. (2009). Family functioning and coping behaviors in parents of children with Autism, Journal of Child and Family Studies, 18 (1) p. 83-92, DOI: 10.1007/s10826-008-9209-y

American Psychiatric Association (2000). Desk reference to the diagnostic criteria from DSM IV-TR, Wachington DC, APA, pg. 59-61

Autism Society of America (ASA). (2008). *About autism*. Retrieved March 5, 2011, from http://www.autism-society.org/about-autism/ http://www.autism-society.org/about-autism/facts-and-statistics.html

Baker-Ericzen, M.J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research & Practice for Persons with Severe Disabilities*, 30*(4)*, Pg. 194-204; ISSN: 15407969

Bourke-Taylor,H., Howie, L., & Law, M. (2010) Impact of caring for a school-aged child with a disability: understanding mothers' perspectives. *Australian Occupational Therapy Journal*, 57, 127–136 doi: 10.1111/j.1440-1630.2009.00817.x

Center for Disease Control and Prevention. (2010). Autism Spectrum Disorders: what you should know? Retrieved August 24, 2010, from http://www.cdc.gov/ncbddd/autism/index.html

Cobb, S. (1976). Social support as a moderator of life stress. *Pschosomatic Medicine*, 38, 300-314.

Dabrowska, A. & Pisula, E. (2010). Parenting stress and coping styles in mother and fathers of preschool children with autism and Down syndrome, *Journal of Intellectual Disability Research*, 34 part pg. 266-280, DOI: 10.1111/j.1365-2788.2010.01258.x

Davis, N. O. & Carter, A.S. (2008). Parenting stress in mothers and fathers of toddlers with Autism Spectrum Disorders: associations with child characteristics, *Journal of Autism Developmental Disorder*, 38:1278–1291, DOI 10.1007/s10803-007-0512-z

Duarte, C., Bordin, I., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *SAGE Publications*, 9(4) 416–427, DOI: 10.1177/1362361305056081

Friedman, M.M. (1998). *Family Nursing research, theory and practice* (4th ed.). Stamford, CT, Appleton & Lange.

Gray, D.E. (2006). Coping over time: the parents of children with autism, *Journal of Intellectual Disability Research*, 50, part 12, pg. 970-976. DOI: 10.1111/j.1365-2788.2006.00933.x

Hastings, R.P., Kovshoff, H., Brown, T., Ward, N.J., Espinosa, F.D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9*(4)*; 377 -391. DOI: 10.1177/1362361305056078

Higgins, D.J., Bailey, S.R. & Pearce, J.C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9*(2)* 125–137, DOI: 10.1177/1362361305051403

Institute of Medicine (2001). Crossing the quality chasm, a new health system for the 21st

century. Washingtone DC: National Academy Press

Kübler-Ross, E. (1975). Death the final stage of growth. Englewood Cliffs, New Jersey, Prentice-Hall

Lazarus, R.S. & Folkman, S. (1984). *Stress, appraisal and coping*. New York, NY: Springer Publisher Company

Lee, L.C., Harrington, R.A., Louie, B.B., & Newschaffer, C.J. (2008) Children with Autism: Quality of Life and Parental Concerns Journal of Autism Developmental Disorder, 38:1147–160, DOI 10.1007/s10803-007-0491-0

Lino, M. (2010). Expenditures on children by families, 2009. U.S. Department of Agriculture, Center for Nutrition Policy and Promotion. Miscellaneous Publication No. 1528-2009. Retrieved April 9, 2011 from http://www.cnpp.usda.gov/publications/crc/crc2009.Pdf

Luther, E.H., Canham, D. L., & Cureton, V. Y. (2005). Coping and social support for parents of children with autism. *The Journal of School Nursing*, 21*(1),* page 40-47. Retrieved May 10, 2010, from http://web.ebscohost.com/ehost/pdfviewer/pdfviewer?vid=2&hid=113&sid=1ae5f247-0d57-495e-a4c8-08834866d0da%40sessionmgr114

Macks, R.J. & Reeve, R.E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders,* 37*(6),* 1060-1067, DOI 10.1007/s10803-006-0249-0

Mandell, D.S. & Salzer, M.S. (2007). Who joins support groups among parents of children with autism? *Autism,* 11(2), 111-122. DOI: 10.1177/1362361307077506

McCubbin, H.I. & Figley, C.R. (1983). Stress and the family volume II: coping with

catastrophe, New York, NY. Brunner/Mazel

McCubbin, H.I. & Thompson, A.I. (1987). *Family assessment inventories for research and practice,* Madison, WI, University of Wisconsin- Madison

Myers, S. M. & Johnson, C. P. & the Council on Children with Disabilities. (2007) Management of children with austism spectrum disorders. *Pediatrics,* 120*(5),* 1162-1182, DOI:10.1542/peds.2007-2362

Phelps, K., Hodgson, J., McCammon S., & Lamson, A. (2009). Caring for an individual with autism disorder: A qualitative analysis. *Journal of Intellectual & Developmental Disability,* 34*(1),* 27-35.

Rice, C. (2009). Prevalence of autism spectrum disorders- autism and developmental disabilities monitoring network, United States, 2006, *Morbidity and Mortality Weekly Report,* 58*(SS10)*, 1-20, Retrieved May 10, 2010 from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm

Rice, V.H. (2000). *Handbook of stress, coping and health: Implications for nursing research, theory, and practice,* London, Sage publications inc.

Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: marital stress and support coping. *Journal of Autism and Developmental Disorders*, 33, 383–394.

Robinson, D.L. (1997). Family Stress Theory: implications for family health. *Journal of the American Academy of Nurse Practitioners,* 9*(1),* pg. 17-23. Retrieved February 25, 2011 from http://onlinelibrary.wiley.com.ezproxy.undmedlibrary.org/doi/10.1111/j.1745-7599.1997.tb01268.x/pdf

Sawyer, M.G., Bittman, M., La Greca, A.M., Crettenden, A.D., Harchak, T.F., & Martin, J. (2010). Time demands of caring for children with autism: what are the implications for maternal mental health? *Journal of Autism Developmental Disorder,* 40, 620–628, DOI 10.1007/s10803-009-0912-3

Sharpley, C.F., Bitsika, V. & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability*, 22*(1)*, 19-28, ISSN: 07263864.

Sivberg, B. (2002). Family system and coping behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism*, 6, 397–409. DOI: 10.1177/1362361302006004006

Tanguay, P.E. (2010). Autistic Spectrum Disorders: Epidemiology. In Dulcan, M.K. (Ed.), *Dulcan's Textbook of Child and Adolescent Psychiatry.* Arlington, VA: American Psychiatric Publishing. Retrieved August 24, 2010, from http://www.psychiatryonline.com/content.aspx?aID=455979

Twoy, R., Connolly, P.M., & Novak, J.M. (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners,* 19, 251–260, doi:10.1111/j.1745-7599.2007.00222.x.