

Understanding Relationships in Health Related Quality of Life for Parents of Children with Autism Spectrum Disorder

Norah Louise Johnson
Marquette University

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UNDERSTANDING RELATIONSHIPS IN HEALTH RELATED QUALITY OF
LIFE OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

by

Norah L. Johnson RN MSN CPNP PhD Candidate

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Marquette University,
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ABSTRACT

UNDERSTANDING RELATIONSHIPS IN HEALTH RELATED QUALITY OF LIFE FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

Norah Johnson RN MSN CPNP PhD candidate

Marquette University, 2009

Nurses encounter many parents of children with autism spectrum disorder (ASD). Both parents are under stress that ultimately impacts their health related quality of life (HRQL). Few studies assess the mediators of parenting stress on HRQL for both parents. This study explored the relationship of parenting stress, family functioning and HRQL for parenting dyads of children with ASD. Lazarus and Folkman's (1984) Transactional Model of Stress and Coping and Lakey and Cohen's (2000) Social Support Theory framed the study.

Implementing a cross sectional, descriptive design, 387 parents (n=64 dyads) of ASD-affected children, from 46 states, completed web-based surveys. Demographics, the Feetham Family Functioning Survey (FFFS), Parenting Stress Scale: Autism (PSS:A), and the Rand 36 HRQL measure were collected. The FFFS discrepancy score (D), quantified differences between expectation and reality. The Rand 36 has a mental (MCS) and a physical (PCS) component scale. A non-parametric Wilcoxon test was used to compare fathers and mothers. Pearson correlation and linear regression were used to analyze relationships.

Females' family functioning discrepancy scores between 'what is' and 'should be' family functioning were significantly wider than males, $p=.002$. The MCS of both parents and the PCS of female parents were negatively related to the stress variables and D scores. For females, higher care-giving stress was related to lower female PCS ($p<.001$), accounting for 22 % of variance in a regression. For females' MCS, a higher D score predicted lower MCS ($p=.001$), accounting for 21% of the variance. For males, personal and family life stress ($p<.001$) and the D score ($p<.001$) were significant in the regression, with the D score accounting for 34% of the variance. Findings extend nursing knowledge about the mediating role of family functioning on HRQL. Interventions focused on expectations about family functioning are indicated.

KEY WORDS: Autism, Autism spectrum disorder, Family Functioning, Parenting Stress, Health Related Quality of Life

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Norah Johnson RN MSN CPNP PhD candidate

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Chapter One: Introduction

Autism spectrum disorder (ASD) is a neurological disorder that affects both the individual and the family. In the individual it affects communication skills, social interaction and behavior (APA, 1994); while in the family it affects interactions with the child, between parents and between the family and the community (Phetrasuwan, 2003). Parenting children with ASD is more stressful than parenting typically developing children or children with other developmental disabilities (Hastings & Johnson, 2001; Konstantareas & Papageorgiou, 2006; Sanders & Morgan, 1997; Tobing & Glenwick, 2006). Because there is no cure for ASD, one recognized metric of a successful outcome for children and their families is improved quality of life (Lantos, 2007).

Nurses have the opportunity to impact the quality of life of the parents of ASD-affected children because nurses come into contact with parents early in the diagnosis process. They also continue to support families throughout the child's life. Advocacy for those in the care of nurses is an important responsibility of the profession (Feetham, 2005). It is therefore important for nurses to have a clear understanding of how best to advocate for improved quality of life for parents of children with ASD.

Social support is considered to be a key factor that aids family resiliency (McCubbin, Thompson, & McCubbin, 1996). Social relationships that provide emotional and informational support help parents cope, but what is not clear is how the components of social relationships serve to mediate health outcomes (Cohen, Underwood, & Gottlieb, 2000; Lazarus & Folkman, 1984). Social

relationships are thought to influence our cognitions, emotions, and biology (Lakey & Cohen, 2000). Coping seems to be affected by the social relationships, and thus the relationships of parents of children with ASD merit further study.

A study that gathers data from both members of a parenting dyad would be the most helpful in understanding what parents find supportive as well as what is stressful. Stress is theorized to be related to health (Lazarus & Folkman, 1984). Parental health is important as parenting a child with ASD is emotionally and physically demanding.

The focus of this study is on understanding the relationship of parenting stress, family functioning and health related quality of life (HRQL) for both parents of children with ASD. Results of the study will guide nurses and other health care providers regarding how to best promote the HRQL for parents of children with ASD. The results of the study could help health care providers develop or refine parenting programs with the goal of improved health related quality of life.

Purpose

The purpose of the study was to gain a better understanding regarding the relationship of parenting stress, family functioning and the health related quality of life (HRQL) for both parents of children with ASD.

Hypotheses

A. High discrepant scores within spouse perceptions of what is and should be in family functioning will be associated with lower HRQL as measured by the Rand 36-Item Health Survey 1.0.

B. High discrepant scores between spouse views of what is and should be in perceived family functioning will be associated with lower HRQL as measured by Rand 36-Item Health Survey 1.0.

Research Questions

1. What is the influence of one spouse's perceived family functioning as measured by Feetham Family Functioning Survey (FFFS) on the other spouse's perceived family functioning?
2. What is the relationship of parenting stress, family functioning and parental HRQL as measured by the Parenting stress: Autism scale, FFFS and the Rand 36-Item Health Survey 1.0 for parents of children with ASD?
3. Does family functioning mediate the relationship between parental stress and parental HRQL?

Background

In the American Psychiatric Association's DSM-IV manual (APA, 1994) the symptoms of autism spectrum disorder (ASD) are organized under the diagnostic

heading: 299.0 Pervasive Development Disorder. Included are five distinct pervasive developmental disorders: 1) Autistic disorder, 2) Pervasive Developmental Disorder, not otherwise specified (PDD-NOS), 3) Rett's syndrome, 4) Asperger's syndrome, and 5) Childhood disintegrative disorder. Currently with the DSM-IV (APA, 1994), a person is diagnosed with autism spectrum disorder if they exhibit symptoms listed within each of three domains. These are 1) qualitative impairments in social interaction, 2) qualitative impairments in communication and 3) restricted, repetitive, and stereotyped patterns of behavior, activities and interests. The symptoms must be 'marked' and must result in 'gross' and 'sustained impairment (APA, 1994).

Some individuals have symptoms in the first two domains or have mild symptoms in each domain. These individuals are described as being on the autism spectrum (Tanguay, Robertson, & Derrick, 1998). However, the term autism spectrum disorder is generally used to indicate individuals with PDD and who may show a broad range of symptom severity (Tanguay, 1999, 2006). Diagnostic agreement for PDD-NOS is generally considered weak as the DSM-IV uses a categorical system which is less useful in encompassing manifestations in a spectrum disorder (Knapp & Jensen, 2006). As research yields new findings, changes in classifications are expected (Knapp & Jensen, 2006).

The prevalence of ASD has increased over the last forty years from 4-5 per 10,000 (Lotter, 1966) to an estimated at 1 in 150 children (Rice, 2007). Rice reports that the increasing prevalence is a public health issue. She recommends efforts to help children with ASD get a diagnosis early in life (Rice, 2007). The

increase in the prevalence of ASD has lead politicians and the media to conceptualize it as an 'epidemic' (Lilienfeld & Arkowitz, 2007). The epidemic conceptualization and the attention that ASD has garnered in the media culminated in 2006, when George Bush signed the 'Combating Autism Act'. The act's intent was to increase public awareness about the disorder and provide enhanced federal support for autism research and treatment (Bush, 2006). By creating a national education program for health care professionals and the public about ASD, the legislation should help more people recognize the symptoms of ASD and get early intervention that may lead to improvement in their condition (Bush, 2006).

Family members of a child with ASD seek support from many different places. Traditionally sources of support include: teachers, therapists, and medical personnel (Deris, 2005) as well as family and confidants (Dean & Tausig, 1986). Families choose supports based on their characteristics and their perception of need. The family members gather information and then appraise the significance of what is happening and determine what they should do about it (Lazarus, 1999). During the information gathering, parents soon learn that there is great variability in the way that other parents care for children with ASD. A research review of the comparative effectiveness of therapies for children with ASD by the Agency for Health Care Research and Quality (AHRQ, 2009) found that while advances have been made in early diagnosis and intervention, there are no current guidelines for comparing the benefits and the harms of treatments. Parents listen to other parents explain what works for them, in their situation, with

their child. Because of a lack of evidence base for most therapy and treatments, parents are vulnerable to persuasive presentations for non-evidence based therapies. Nurses can play an important role in advocating for parents so that they find the evidence based assistance that the parents experience as helpful.

In the last 15 years a new support for gathering information is the Internet, which provides a public forum for literally any group concerned with ASD to share its knowledge and support. As such, the Internet can be a tremendous resource for parents. Many people own personal computers that have Internet access and computers are available at local libraries. Where once parents could only interact face to face with health care professionals, family and friends for support and information, parents coping with the diagnosis of autism today can employ the rich tool that the Internet is, anonymously, if they wish, and certainly at some level of interpersonal distance if they feel the need.

However, accessing the Internet and on-line support groups may only help reduce the impact of some of the diverse challenges that families face. Competent facilitators help parents problem-solve. Often, facilitators are lacking in on-line support groups or forums (Wellman, Haase, Witte, & Hampton, 2001). In addition, the relationships one develops, on-line, with others may be individualistic and easily revocable (Hsiung, 2000) and inferior to face-to-face or telephone communication (Wellman et al., 2001). As such, there is concern that on-line communication may serve to divert people from their supportive community. A supportive community is one that is reliable and trust-worthy. It implies a deeper relationship than what one might envision being possible

electronically. Regardless, parents seek information about ASD on the Internet. In America, there are several national organizations that provide information that parents can access. These include: Autism Speaks (Autism Speaks, 2007), Cure Autism Now (recently joined to Autism Speaks), the Autism Society of America, and the National Autism Association (National Autism Association, 2007). A 2009 addition to the supportive community for parents of children with ASD is the Interactive Autism Network (IAN) (<http://www.iancommunity.org>). This site has a discussion board with a PhD prepared moderator on staff at IAN. Users must log in and agree to user policy before posting discussion items. IAN is supported by Autism Speaks (<http://autismspeaks.org>), which also has a message board, with approximately 3583 registered members, where parents can post questions and answer those posted by others (Autism Speaks, 2007). However, it appears that the ratio of those members who participate on this board is higher for women. For example, on December 16, 2007, on the Autism Speaks message board, there were 21 posts, 20 of which appear to have been placed by women, based on the username (Autism Speaks, 2007). While this example is anecdotal rather than the result of a formalized research study, it none the less highlights a phenomenon that lies at the core of this study: the relationship among parenting stress, family functioning and HRQL may differ for mothers and fathers of children with ASD. While all marriages call for mutual support, having a child with autism intensifies that need for support as the child's needs become a component of the parental relationship (Marciano, 2005).

Two recent studies highlight attention to the ongoing and critical lifetime challenges of people living with ASD that impact their parents' HRQL. In the first study, Easter Seals (2009) surveyed 1652 (8% male, 92% female) parents of children age 30 or younger with ASD. The majority of the children were male (85%). Forty-three percent of the children were over 19 years old. Data was collected from a Harris Poll and was weighted to be representative of the U.S. population on the basis of gender, education, region, household income, and race/ethnicity. Data from a control group of parents of children aged 30 or younger without special needs (n=917) was collected for comparison. The survey asked parents what concerned them about the child's future. Concerns included their child's independence, financial well-being, quality of life, fitting into society, employment prospects, housing, and independence. These concerns remain high as the child with ASD grows, whereas in the control group the concerns decreased. Day-to-day routines are more time consuming for parents of ASD-affected children than the parents in the control group. Parents reported that they receive little support from their extended families, but 40% did receive some support from the government such as special education and Medicaid.

The second recent comprehensive study of parents of children with ASD reported preliminary results on the Interactive Autism Exchange website (IAN, 2009). Data was collected from 4682 parents (88% mothers) of children with ASD, using a web-based survey. Parents rated the impact of having a child with ASD on the couple's relationship as somewhat or very negative for 60%% of mothers and 54% of fathers. Researchers report a variety of supportive and

unsupportive family situations. The division of labor was the most common contributor to marital conflict (IAN, 2009).

Both the Easter Seals and the IAN exchange studies attempted to gather data about the stress of parenting on the couples' relationships. However, neither study collected data from both parents of the parenting dyad. The overwhelming numbers of participants were women. The present study assesses the family functioning expectations for both males and females in the parenting dyad.

Family functioning is a concept prevalent in the study of families. Members of families of children with autism form relationships between individuals, the family and subsystems (relatives, friends, neighbors), and the family and broader community (work/schools). The relationship is known to be the fundamental ingredient in the concept of social circles or social networks (Lin, 1986).

Relationships are characterized by people spending time with each other, emotional intensity, intimacy (mutual confiding) and reciprocal services (Lin, 1986). The design of an effective study and subsequent development of interventions requires careful consideration of relationships among variables occurring in social relationships as determinants of health outcomes (Cohen et al., 2000).

Need for the Study

A study that assesses both fathers and mothers allows one to sample the variations in perspectives among family members (Martin & Cole, 1993). The possible strain on the parents in relation to the HRQL of the parents merits

investigation. A particular emphasis for this study was the gathering of data from fathers since this has been a poorly sampled demographic according to the literature review to follow. Gender differences in relation to family functioning, parental stress and HRQL, were an important part of the research. Examining the parental dyad in partnership with each other, providing shared-care for the child with autism, has not been well studied.

Chapter Two: Review of Literature

In this section I will address the conceptual and philosophical underpinnings of the study and the two theories that this study was based on: 1) The Stress and Coping Theory (Lazarus & Folkman, 1984); 2) The Social Support Theory (Lakey & Cohen, 2000). I will also provide the conceptual definitions and a review of relevant literature.

Conceptual and Philosophical Underpinnings

The conceptual underpinnings of the study were based on Lazarus (Lazarus & Folkman, 1984). The concept of vulnerability, also frames the study. Lazarus posits that the human mind works by means of structure and processes. He describes structure as the relatively stable arrangement of things, and process as what structures do and how they change (Lazarus, 1999). Our thoughts and emotions are processes. The key assumption with this philosophical approach is that our thoughts and emotions are changeable.

Lazarus (1999) considered habits and action styles as structures since they have been acquired from learning and remain fairly stable over time. Structures are more stable and are easier to measure than processes. One example of a structure is intelligence (Lazarus, 1999). A score for intelligence, known as an intelligence quotient (IQ) can be measured by the Wechsler Adult Intelligence Scale (Wechsler, 1958). IQ is relatively stable as it is thought to have a biological basis. People with higher IQs generally have larger brains with

apparently faster neural conduction speed (Deary & Caryl, 1998). The biological basis of intelligence makes it less likely to be changeable, and therefore less able to be impacted by an intervention.

Intelligence, as a structure, is different from a process. Processes are organized, patterned, and enduring sequences of mental events (Pulver, 1988). However, processes are more subject to change through an intervention. Nursing involves assessing, planning, implementing interventions, and evaluating effectiveness of interventions. Nurses identify processes that are amenable to an intervention. Interventions can be tailored for processes, with the goal of improving outcomes. For example, a nurse could tailor an intervention to an identified process that impacts the outcome of health related quality of life for the parent.

Family functioning is considered a process (Roberts & Feetham, 1982). It is, theoretically, changeable by an intervention. Family functioning is considered a process as it involves relationships the family has with individuals, the family and subsystems (relatives, friends, neighbors) and the family and broader community (work/schools) (Ferrans, Zerwic, Wilbur, & Larson, 2005). Two processes in relationships are perceptions and expectations. These processes are made up of thoughts and emotions.

The parents of ASD-affected children are vulnerable because of the chronic nature of the condition. Next, I will present literature related to the concept of vulnerability.

Vulnerability

Children with ASD, and their parents, are vulnerable to unfavorable outcomes. To be vulnerable is to be susceptible to harm or neglect including acts of commission or omission on the part of others that can wound (Aday, 2001). To be vulnerable is to be physically or psychologically weak, unable to resist illness, debility, or failure (Flaskerud, 2002). Children with ASD qualify as a vulnerable population. Children and their parents may experience health disparities as a result of lack of resources and or increased exposure to risk. Aday explains the epidemiological concept of risk. Risk is the probability that an individual could become ill within a given period of time. Consequences of vulnerability from poor health include physical, mental, and social. Although everyone is at risk of developing health problems, the risk is greater for those with the least social status, social capital, and human capital resources to either prevent or ameliorate the origins and consequences of poor physical, psychological or social health (Aday, 2001). Parents of children with ASD are at risk of mental and physical health problems.

Kawachi and Berkman (2000), outline the theoretical and empirical linkages between social cohesion (and its related concept, social capital) and health. Social cohesion is defined as the connectedness and solidarity among groups in society. Social capital is defined by James Coleman (1990) as those features of social structures—mutual trust, norms of reciprocity and mutual aid—that facilitate the actions of the members within them (Coleman, 1990).

Navigating the health care system is not easy. It can be an emotional and financial strain on parents (Sallows & Graupner, 2005) and ultimately affect their physical and psychological health (Bromley et al., 2004; Epel et al., 2004; Palmer, 2004). Nurses can help parents navigate the health care system. Next, I will present several assumptions that undergrid the study.

Assumptions

Several assumptions under grid the study. A quantitative methodology was indicated for the present study. This approach is based on the assumption that individuals will answer questions on the instruments honestly and that representations about the nature of reality can be made from these responses. It is assumed that relationships, mediating variables and ultimately predictors of health-related quality of life for parents of children with ASD can be discerned.

The predictors of health related quality of life for parents of children with ASD are best understood in the context of their relationship with the other parent. This assumption flows from assumptions of the theoretical framework. The transactional model of stress and coping (Lazarus & Folkman, 1984) views the person and the environment in a mutually reciprocal, bidirectional relationship.

Gap in Literature

There is a gap in the literature on dyad data looking at the relationships of family functioning, parenting stress and parental HRQL. There has not been a study looking at this relationship for parents of children with ASD.

Theoretical Frameworks

Stress and Coping Theory. The first theory that frames the study is the Transactional Model of Stress and Coping. In this model, Lazarus and Folkman (1984) conceptualize that the way that people cope with stress, rather than the stress per se, impacts their physical, social and psychological well being. Lazarus and Folkman (1984, p.141) define coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984). They acknowledge that the appraisal of the stress can vary from person to person.

It is the appraisal of the stress that is important. If one feels supported it may have a positive effect on their health. Support from a social network can help people feel good, and can ‘buffer’ the stress by either making the stressor seem less threatening or by providing resources to cope with the stress (Lazarus & Folkman, 1984). Support builds resiliency (McCubbin & McCubbin, 2001) which may then help improve HRQL.

The Transactional Model of Stress and Coping is an important theory for framing the study. In addition, the Social Support Theory gives clear guidance for conceptualizing family functioning in a supportive role to mediate the potential effect on parental HRQL as shown in Figure 1.

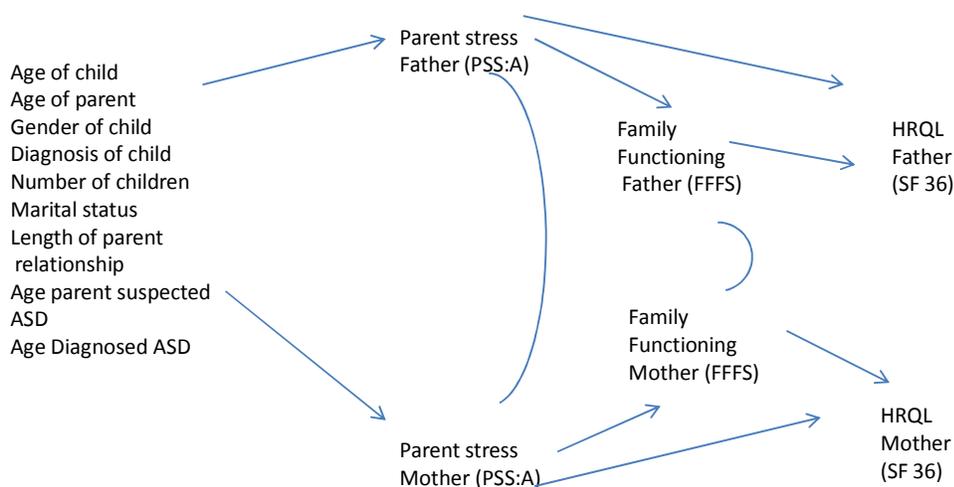


Figure 1 Conceptual Model: Johnson Parenting Health Related Quality of Life Model

(Adapted from Lazarus and Folkman, 1984; Lazarus, 1999).

Social Support Theory. Social relations influence our cognitions, emotions, behaviors and biology (Lakey & Cohen, 2000). The effects of social support include a person's adherence to health behaviors and a person's immune response. Generally, close relationships are thought to contribute to a person's perception that support is available if needed (Lakey & Cohen, 2000). The social support model assumes that processes operating within relationships matter most as opposed to just the existence of a relationship (Reis & Collins, 2000). Processes are organized, patterned, and enduring sequences of mental events (Pulver, 1988). The processes in relationships include our thoughts and emotions. Relationships and social interactions are key to understanding how our interpersonal lives influence our health (Cohen et al., 2000).

Concepts

The purpose of this study, to explore whether individual perceptions of family functioning mediate the association between parenting stress and HRQL for parents of children with ASD, suggests a quantitative analysis. Several concepts are involved. Concepts are building blocks from which theories are constructed (Rogers & Knafel, 2000). They reflect all the contextual forces that shape their development and variation as well as their use (Rogers & Knafel, 2000). The concepts in this study include parenting stress, family functioning, and health related quality of life (HRQL). These concepts will be briefly described.

Parenting Stress. Lazarus and Folkman (1984) developed the theory of stress that involved appraisal and coping as determinants of one's health

outcome. In the theory, mental processes are involved in the determination of whether or not stress occurs. They view stress as a physiological and psychological response to situations that require some form of a response. The amount of stress appraised depends on resources one has available, in this case support through family functioning.

Building on the earlier work, Lazarus (1999) subsequently developed a more contextual view of stress. The definition of stress in the present study is as follows: "Stress and how it is handled depends on numerous distal and proximal variables, such as gender identities, functional relationships between husband and wife, and the conditions of work in which each is engaged" (Lazarus, 1999, p.133). For parents of children with ASD, the way stress is handled may depend on support through family functioning.

Family Functioning. Families of children with ASD face a life long battle with a chronic disorder of communication, behavioral and socialization difficulties. Parents benefit from supportive actions of others. The family itself can be supportive. Knafl and Deatrck, (2003), developed a family management framework. The framework describes family responses to chronic conditions. The framework is based on themes from 46 studies focusing on the family response to childhood chronic conditions. One theme is parental mutuality. They define parental mutuality as: "Parental views of the degree to which they hold shared or discrepant views of the child, the illness, their parenting philosophy and their approach to illness management" (Knafl & Deatrck, 2003, p.244). The literature suggests that parents vary in the extent to which they hold shared views of the

illness situation. The authors report parents adapt family roles and relationships to meet the demands of illness (Knafl & Deatrick, 2003).

Support and family functioning are two separate but related concepts. Family functioning has been defined as a set of basic attributes about the family system that characterize and explain how a family system typically appraises, operates, and/or behaves (McCubbin & Thompson, 1991). In the present study, the definition of family functioning is as follows: Family functioning includes supportive relationships among parents, family members, friends and community members (Roberts & Feetham, 1982).

Psychometrics of the Feetham Family Functioning Survey support three conceptual domains: individual, subsystem and the community (Roberts & Feetham, 1982). The conceptual domains for the FFFS, suggest that there is a connection between the individual, subsystem, community, and social support. Social support was a predictor of family functioning (Roberts & Feetham, 1982). The theoretical foundation for the FFFS is an ecological framework. As an ecological framework, the family system is assumed to be in a dynamic state of change. The family is viewed from a systems perspective. Family members are interdependent. They interact with each other and the environment. The interactions lead to family development.

Support contributes to health by protecting people from the adverse effects of stress (Lakey & Cohen, 2000). Social support reduces the effects of stressful life events on health through either the supportive actions of others (e.g., advice, reassurance), or the belief that support is available. Situations are

perceived as less stressful when support is perceived to be available (Lakey & Cohen, 2000).

Sharpley and Bitsika (1997) report that families find knowledgeable family members to be their greatest support. In the quantitative study of 219 parents of children with autism (n=141 females, n=78 males) the researchers assessed parental well being (anxiety, depression), parenting stress and their confidence in handling their child's major difficulty as well as the frequency of being stretched beyond their limit. The majority of the children were less than nine years old (75%) but the ages ranged from 3 to 22 years. The independent variables were gender of the parents, age of the child at onset, parental health, access to other family members, and the level of understanding of those members of the child's problems. Respite by family members was only considered to be a source of support by the parents when the respite care was provided by a knowledgeable provider. Parental well-being was not significantly different according to the relationship the parent had with the immediate family member who gave assistance, instead, significant main effects related to the level of understanding which parents felt their immediate family member had of the child's problems. The belief in the family member's ability also impacted the parent's self confidence in caring for their child. From this study it is clear that it is not just having respite that was considered supportive, but rather having knowledgeable providers for respite, regardless of whether or not they are family members.

Health Related Quality of Life. Wilson and Cleary (1995) explored the concept of health-related quality of life (HRQL). They characterize HRQL as

subjective well-being related to how happy or satisfied someone is with life as a whole (Wilson & Cleary, 1995). Health outcomes are integrated between two different paradigms (clinical/basic science and social science). In the clinical paradigm, the focus is on etiologic agents, pathological processes, and biological, physiological, and clinical outcomes. In contrast, the social science paradigm focuses on dimensions of functioning and overall well being. Ferrans recognized that the term quality of life was being used to represent a variety of different things (Ferrans et al., 2005). The term HRQL was introduced to narrow the focus of the effects of health, illness and treatment on quality of life.

Nursing research, and policies affecting families, emphasize the outcome of health and well-being (Feetham & Meister, 1999). Family functioning plays a role in health and illness. Therefore, the present study will focus on the identification of interrelationships between parenting stress, support from family functioning, and HRQL, for parents of ASD-affected children.

Critical Analysis of Literature

A literature search was undertaken in the following data bases: CINAHL (all years), Health Sciences in Proquest (all years), Social Sciences in Proquest (all years), PSYCH info (1985 to the present), ERIC, MEDLINE (1996 to present), and Dissertations and Theses Abstracts using the keywords: autism, dyads, social support, stress, health related quality of life, and well-being.

Sixty years ago mental health professionals who diagnosed autism held on to the theory that parents (mothers in particular) were causal agents in their

child's condition (Hyvonen, 2004). As a result, parents not only had the challenge of caring for a child with ASD but also had strained relationships with health care providers. Professionals now dismiss the parent blaming theory (Hyvonen) but it is important to understand the historical background regarding parenting stress, support and parental quality of life.

Past efforts with quantitative research methods to understand how parents adjust to the stress of parenting a child with ASD focused on the degree of the child's disability (Diamond, 2006; Hastings & Johnson, 2001), the social support available to the parents (Bromley, Hare, Davison, & Emerson, 2004; Diamond, 2006; Tobing & Glenwick, 2006) and parents' coping style (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001a). In the majority of the studies, researchers typically report findings from individual parents, such as the mother or the father. The majority of the participants in these research studies were mothers, and thus a majority of research findings about parenting a child with autism relate to women. What follows is a review of literature by the concepts parenting stress, support, and HRQL. The first concept reviewed is parenting stress.

Parenting Stress. Parents of children with ASD are particularly stressed by the characteristics of the condition itself. These include: sleep disturbances (Hoffman et al., 2008), temperament, toileting, communication and learning disabilities (Randall & Parker, 1999). The severity of the behaviors of the child with ASD has been associated with parenting stress (Brobst, Clopton, & Hendrick, 2009; Estes et al., 2009; Hastings & Johnson, 2001; Herring, Gray, Taffe, Sweeny, & Einfeld, 2006; Tobing & Glenwick, 2006).

Effective communication with an autistic child requires knowledge of the condition combined with a calm approach so as not to increase the child's anxiety (Browne, 2006). Some children only have mild difficulty with communication, social interaction, and behavior (APA, 1994; Tanguay, 1999). However, some children do not have any effective means of communication or social interaction and have significant behavioral challenges. The family-members of the child with ASD labor in interacting with the child, and physically caring for them (Baker, Blacher, & Olsson, 2005; Randall & Parker, 1999).

Past studies have centered on understanding the child characteristics that contribute to maternal parenting stress and psychological distress. Sleep difficulties and severity of autism were indicative of mothers' stress in a study of 72 mothers (Hoffman et al., 2008). The GARS-2 (Gilliam, 2005) was used to evaluate autism symptoms. Sleep was evaluated with the Children's Sleep habits Questionnaire (Owens, Spirito, & McGuinn, 2000), and the Parenting Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). Parenting Stress was measured with the Parenting Stress Index (Abidin, 1995). Results were based on mothers' retrospective reports. Mothers' reports of sleep problems with their children were related to mothers' reports of their own stress, even after controlling for the mothers' own sleep problems and severity of the child's autism.

Estes et al. (2009) found that problem behavior is associated with elevations in parenting stress and psychological distress in mothers. The sample included 74 mothers of pre-school aged children (n=51 with ASD, n=23

developmental disability [DD]). The researchers found that children with ASD had more problem behaviors than the children with DD. They also found that the problem behaviors were more strongly related to the maternal parenting stress and psychological distress in both the ASD group and the DD group. The study was well designed and used reputable measures. The two groups of children were matched on non-verbal mental age at the outset of the study. Autism diagnosis was verified using two standardized psychological tests (ADI-R and the ADOS-G). Stress was measured using the self-report 78-item Questionnaire on Resources and Stress (Konstantareas, Homatidis, & Plowright, 1992) that measures the stress and burden of care in families of children with disabilities. Psychological distress was measured with the Brief Symptom Inventory (Derogatis & Melisaratos, 1983). Two tools were used to measure behavior: the 58-item Aberrant Behavior Checklist (Aman & Singh, 1986) and the Vineland Adaptive Behavior Scales Interview Edition (Sparrow, Balla, & Cicchetti, 1984). The researchers note that participating families may be a unique subset of the population of families with disabilities in that they have the time and the energy to participate in this longitudinal study. The findings, that problem behavior contributed to parenting stress and psychological distress in both groups of parents is important. The behaviors of all the children in the study, not just the autistic children, contributed to stress and distress in parents. Interventions focusing on reducing problem behavior were indicated.

There were also reports in the literature about stressors beyond those of the child's behavior. Stressors included: obtaining the correct diagnosis

(Whitaker, 2002), the urgency to take immediate action (Coucouvanis, 1997; Filipek et al., 2000; Giarelli, Souders, Pinto-Martin, Bloch, & Levy, 2005; Johnson, 2006) and conflicting information (Johnson, 2006; Konstantareas & Papageorgiou, 2006), much of which concerns controversial treatment selection (Apel, 2002). Many treatment strategies are not empirically shown to improve the symptoms of ASD (AHRQ, 2009; Carey, 2004; Fombonne, 2003).

Gender is another variable that is discussed in literature on stress, coping and illness. Mothers, rather than fathers of children with ASD, are a source of the majority of the research on parenting stress and psychological distress. The Interactive Autism Network reported that in July 2009, 1000 fathers enrolled to participate in research studies but that women still outnumbered men 8 to 1 in study participation (Anderson, 2009). Montes and Haltherman (2007) found that mothers were more stressed and more likely to report fair or poor mental health than mothers in the general population. The mothers were surveyed in the American National Survey of Children's Health, a population based study. In this study children were identified as having autism by asking the mother if the child had autism. Three-hundred and sixty-four mothers out of 61,772 children aged 4 to 17 years old, responded 'yes' when asked if a doctor ever told them their child had autism. These 364 mothers were more stressed and were more likely to report fair or poor mental health than mothers in the general population, even after adjustment for the child's social skills and demographic background (Montes & Haltherman, 2007).

In studies including both parents, mothers of children with ASD are reported to have higher stress levels than fathers (Gray, 2002, 2003; Hastings et al., 2005; Little, 2002; Montes & Halterman, 2007). Gray (2002, 2003) collected data in a qualitative study of 32 mothers and 21 fathers of parents of children with high functioning autism. The children ranged in age from 5 to 26 years with a median age of 12 years. Gray described the stress of the social stigma experienced by parents during shopping excursions where on-lookers stare, or comment to the parents about the child's poor behavior. Mothers tended to be the primary care-giver and thus assumed a higher degree of responsibility as well as guilt for the child's behavior than the fathers. Reported coping strategies included ignoring onlookers, and lessening contact with people and situations where they were more likely to encounter bad reactions. These strategies put mothers at risk for isolation.

The disproportionate impact of parenting stress on mothers is addressed by Little (2002). Research findings included that mothers reported more stress and were more pessimistic about the future than fathers. Mothers perceived greater stress for themselves and other family members and the family as a whole. Little writes that one explanation for the higher maternal rates of stress in the study may be that fathers have more outlets for evaluating their self-worth in terms of careers and ability to provide for their families. Little sampled children with Aspergers syndrome and nonverbal learning disorders, using a repeated measures design, controlling for severity and the nature of the child's disability. The sample included 103 matched couples of children with a mean age of 10.57

(SD=3.74) years from a sample of 411 participants recruited on 2 websites on the Internet. Stress was measured using two subscales of the Questionnaire on Resources and Stress-Short Form (Friedrich, Greenberg, & Crnic, 1983). Coping was measured with two subscales of the Coping Health Inventory for Parents (McCubbin, Cauble, & Patterson, 1982). None of the child or parent characteristics were significantly correlated with the scale. Of the child and parent characteristics, child's age was positively correlated with pessimism scores; for mothers ($r=.26$, $p<.008$) and for fathers ($r = .29$, $p<.003$). Parents were more pessimistic about older children than younger children, perhaps as a result of a loss of hope that they once had when the child was young. Maternal education was significantly correlated with pessimism: less educated mothers reported more pessimism than better educated mothers ($r= -.39$, $p<.0001$). It is a complex job to maneuver oneself through the role of advocating for a child with ASD. Education level affects one's ability to find resources.

One study (Clark, 2007) did not find a gender difference in parental stress. However, only 9% of the sample was men. The small percentage of men could indicate a response bias. Clark also found that behavior difficulty was highly correlated with parent stress levels, while no other parent or child characteristics were related to parent stress. In her study, Clark evaluated the potential mediating effects of parental attitudes, such as parent attribution and self-efficacy, on stress levels among parents of children with ASD. This study included 259 parents, 225 of which were parents of children with ASD. Parental stress was measured with the Parenting Stress Scale (Berry & Jones, 1995).

Other literature focused on predictors of parenting stress. Hastings and Johnson (2001) surveyed 141 parents of ASD-affected children and assessed stress, coping, and support. Using regression analysis, predictors of stress were determined to be psychological rather than the demographic variables. Predictors included: perception of informal supports and belief about the efficacy of receiving applied behavior analysis. The presence of severe autism symptoms was related to higher reports of stress. The findings add to the literature above noting that in many cases when children have severe autism, parents have higher levels of stress.

Herring et al. (2006) is one of very few studies that reflect findings from both parents. Herring studied both parents of 123 children, 20-51 months old. Parents completed a checklist on child behavioral and emotional problems, and individual questionnaires on family functioning, their own mental health, and stress in relation to parenting their child. The child's language and cognitive skills, adaptive functioning and behavior were assessed by standardized measures. Measures were repeated a year later. There was a comparison group of children without Autism. Results showed that parent health problems, parent stress and family functioning were significantly correlated, with some evidence of stability over time. Child emotional and behavioral problems contributed significantly more to mother's stress, parent mental health problems, and perceived family dysfunction than did child diagnosis (PDD/non-PDD), delay or gender (Herring et al., 2006).

Interestingly, Phetrusuwan (2003) did not find a significant effect of the severity of ASD, the child's age, or child's gender on parenting stress. Data was collected by self-report. The sample included 108 mothers of children with ASD. The mean age of the child was 6 years old ranging from 3-10 years old. Stress was measured with the Parental Stressor Scale: Autism (PSS:A, Miles & Phetrusuwan, 2003), and the Center for Epidemiological Studies Depression Scale was used to assess depressive symptoms (Radloff, 1977). The mothers rated the child's unusual fears to be the most significantly abnormal characteristic of their child. Problems related to adapting to change and emotional responses were next in severity. She found that mothers who had a lower perception of family satisfaction (less family support) exhibited more depressive symptoms (Phetrusuwan, 2003). This is an important finding. The concept of support as a mediator of parental HRQL is indicated by her findings. Beliefs about supports seem to be important in impacting the effect that the severity of the symptoms ultimately has on the parent's health when their child has behavior problems. Literature on family functioning will be reviewed next.

Family Functioning. When parents of children with ASD are confronted with stress, they seek support in many places. Many parents look to other parents for support (Johnson, 2006). Johnson interviewed 30 parents of children who were suspected to have ASD or were diagnosed with ASD about the supports they found useful. The majority of the participants were Caucasian (53%) women (90%), with a college degree (70%). Parents ranked the order that they tend to use resources, from most used to least used, as follows: Internet,

books, health care professionals, friends, the regional center, and other parents. However, those same resources were cited in reverse order for their usefulness. Mothers reported that there is conflicting information and generally an overwhelming amount of information on the Internet (Johnson, 2006). They wanted to talk to people with experience that they could trust.

Because of the perceived negative societal reactions, parents of children with ASD may decide to rely on their own family as supports. In a review of literature of 46 studies of families facing chronic illness, Knafl and Deatrick (2003) found that the goal of leading a normal life was the guiding principle for many families. Families note the importance of developing a routine and balancing the demands of the child with the chronic condition with the other aspects of family life. Parents have reported joint efforts to manage illnesses, but are known to have different views on how they define and manage the situation (Knafl & Deatrick, 2003). The differences in their views could affect how the family functions. This difference in views is an important concept in this study. The joint effort of parents working together but with different future expectations and or plan to get there is a potential source of distress.

Families must learn to manage the many internal and external resources they encounter. Looman (2004) posits a connection between relationships (interactions between people) and population health. In a descriptive study, 23 parents of children with special health care needs participated in focus groups. Healthy relationships are protective. In a qualitative study of parents of children with chronic health conditions, Looman found that there has been a shift in focus

from support as a commodity to support as an outcome of a social process (Looman, 2004). Supports would not be measured in terms of the number of them. Support would be measured, rather, by one's perception of the value of the support.

Tobing and Glenwick (2006) report that the number of social supports and coping strategies were not significantly related to parental distress. It was not the support itself, but rather whether the support met the parents' expectations that was integral in the outcome of maternal distress in the study. The researchers recruited 97 mothers of children with ASD. In the study, mothers filled out questionnaires capturing the level of the child's impairment, parenting stress, number of social supports, satisfaction with social support, parenting sense of competence, number of coping strategies, and maternal psychological distress. The mothers' parenting competence and the mothers' satisfaction with social support were negatively related to maternal distress. The researchers also found that the child's level of functional impairment was related to higher levels of parenting stress and psychological distress for mothers of children with a range of ASD.

While many studies only sample mothers, communication and coping involve examination of how the two parents work with their child individually and together. In a study of 67 families of children with developmental and intellectual disabilities, both mothers and fathers filled out questionnaires that measured the concepts of depressive symptoms, parenting stress, parenting efficacy, child functioning, child behavior problems, social support and marital quality (Kersh,

Hedvat, Hauser-Cram, & Warfield, 2006). Depressive symptoms were measured with the Center for Epidemiological Studies-Depression Scale (Carter, 2004). Mother and father data were analyzed separately using parallel hierarchical regression models. Marital quality was measured by the dyadic adjustment scale (Spanier, 1976). Cronbach alphas were acceptable at 0.95 for mothers and 0.92 for fathers. Parenting stress was measured with the Parenting Stress Inventory (Abidin, 1995). For both mothers and fathers, greater marital quality predicted lower parenting stress and fewer depressive symptoms above and beyond socioeconomic status, child characteristics and social support (Kersh et al., 2006).

Deris (2005) studied twenty couples (father-mother dyads) of children between ages three to five who were diagnosed no more than a year and a half with ASD. The parents completed a Q-sort which involved ranking items they identified as being supportive from most important to least important. Overall, fathers ranked financial help for expenses the highest. Mothers ranked emotional types of support including 'having someone to talk with about problems, feelings and attitudes' as the most supportive. Fathers and mothers in this study clearly had different views of what they deemed as support.

Another area of interest includes parenting programs. Parents often have the option of enrolling in these parenting programs at local Autism Societies. There is variability in the focus of the program and in participation. Campbell and Kozoloff (2007) stress the importance of parent training for parents of children with ASD. Their rationale is that family is the constant in the child's life whereas teachers and social policies change over time. Parenting programs address the

stressors that could lead to marital stress and career disruption as well as health problems and unproductive interactions with children. Parenting programs help parents make education and program planning decisions. They also help parents have expectations for the child's academic goals and social gains which can include help setting up a home educational program that compliments a school program for maximum effectiveness (Campbell & Kozloff, 2007). Parents are better able to advocate for their children with teachers and health care professionals if they have training.

One program aimed to teach parents to manage and reduce ritualistic and rigid behaviors is the 'Mindful parenting program (Malmberg, 2007). A program evaluation involved sampling five mother-child dyads (Singh et al., 2007). The goal of the program is to train parents in the philosophy and practice of mindfulness. Mindfulness was defined as having a clear, calm mind that is focused on the present moment in a non-judgmental way . After mindfulness training the parents were able to decrease aggressive behaviors and increase the child's social skills. Parents reported increased satisfaction with their parenting, more social interactions with their children and lowered parenting stress (Singh et al.). Even though this was an all female sample it is an important finding. Behaviors of children are one of the greatest causes of parent stress. A program that decreases that stress by providing strategies for a parent is an intervention that is promising as a support for parents of children with ASD.

Winter (2005) found low rates of fathers participate in parenting programs and studied ways in improve attendance by creating a father-focused package

when teaching Pivotal Response Training. Researchers found that a tailored intervention, focused on the father improved attendance. They included a recreational component in combination with the naturalistic therapeutic technique. The ultimate goal was to increase the child's language and play skills.

Stress and supports impact parental psychological and physical health and well-being which in turn affect the quality of life of the parents. Literature on parental well-being and physical and mental health such as distress and depression were reviewed and are included next under the concept heading of parental health related quality of life.

Health Related Quality of Life. The parenting process involves stressors that often impact the parents' psychological and physical health and well-being (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001a, 2001b; Gray, 2003b; Hastings, 2003; Phetrasuwan, 2003; Allik, Larsson, & Smedje, 2006). The recognition of the symptoms of ASD and receiving the diagnosis for a child necessarily has an impact on parents.

Parents are saddened at the time the child is diagnosed with ASD. The diagnosis of ASD is life-altering. The effect that the diagnosis has on the parental quality of life is sadness, stress, and anxiety about getting their child help. The quality of life for parents is important as parents need to be happy, and physically and mentally healthy to keep pace with ASD affected children.

Gender of the parent or the child is a variable that is discussed in the literature on quality of life. Bristol, Gallagher and Schopler (1988) studied the extent to which the presence of developmentally disabled male children (autistic

and severe-communication disorders confirmed with a Child Autism Rating Scale) affected adaptation and family roles for both mothers and fathers. Fifty-six two-parent families with white boys aged 2 to 6 years old participated in the study as well as 31 with developmentally disabled boys and 25 with non-disabled boys. Spousal support was measured using the Carolina Family Responsibilities Scale (Gallagher & Bristol, 1981). Parental adaptation was measured using the Center for Epidemiologic Studies Depression Scale (Radloff, 1977). Results showed that fathers were found to take less responsibility for the developmentally disabled children than the healthy children. How well mothers functioned in these families, in terms of depression, marital adjustments and parenting seemed to be related to the amount of spousal support. Protective factors that help parents manage stress, regardless of the severity of a child's disability, included: parent characteristics, family relationships and social supports (Bristol, Gallagher, & Schopler). Although this study is twenty years old, the tool used to measure spousal support is of interest. This tool has 3 subscales: 1) care of the study child (9 items), 2) general household tasks (15 items) and 3) care of siblings (5 items). The questions assess both 'who is responsible for tasks' and 'who should be responsible for tasks' of child care, chores and sibling care. A disharmony score is computed which is the absolute of the difference between the current and the appropriate scores. The Cronbach's alpha was 0.72 for the total scale and 0.85 for the care of the study child subscale. The scale was never published but is a similar type of assessment scale as the Feetham Family Functioning Survey (Roberts & Feetham, 1982. Both tools use an absolute difference score

between observed and expected outcomes related to support for spouses.

Bristol, Gallagher and Schopler concluded that the mothers of developmentally disabled children carry a disproportionately heavy burden than fathers. How well mothers of disabled children function in terms of depression, marital adjustment, and parenting appears to be related to their partner's capacity to be supportive. How well fathers function, particularly as parents is related to perceived support from their wives (Bristol et al.).

Stress related to the child's behavior and the coping strategies are discussed in the literature in relation to parent well being. Bromley et al.(2004) found that over half of the mothers screened positive for significant psychological distress associated with bringing up a child with challenging behaviors and low levels of social support. In a study of 68 mothers of children with ASD, more of the mothers who perceived lower levels of social support, were a single parent, living in poor housing, or were the mother of a boy with ASD (Bromley et al.). The presence of social support, rather than an assessment of whether or not the parent felt the social support met their expectations, was the measure that researchers used when looking at relationships between support and distress.

The severity of the child's behavior is thought to be related to parental health and well-being. In a study of 214 three to four-year old intellectually disabled children; researchers assessed mothers' and fathers' well-being and child behavior problems. Parents of both the delayed and non-delayed children in the sample did not differ on depression or marital adjustment, but child behavior problems were strongly related to scores on both measures. However, optimism

was found to moderate psychological well being for mothers. The authors recommend parenting programs aimed to increase the mother or the father's dispositional optimism (Baker et al., 2005).

Behavior problems such as hyperactivity and conduct problems in children with Asperger syndrome (AS) and high-functioning autism (HFA) are related to poorer maternal physical health (Allik et al., 2006). The sample included 31 mothers and 30 fathers of 32 children with AS/HFA and a matched sample of children with normal development (30 mothers and 29 fathers). Parental HRQL was measured with the 12 item Short Form Health Survey (SF-12) which measures physical and mental well-being. Behavior was measured with the Strengths and Difficulties Questionnaire (ASSQ). Mothers had lower SF-12 scores than the controls indicating poorer physical health. The mothers also had lower scores compared to the fathers (Allik, Larsson, & Smedje, 2006).

Coping by distancing and trying to forget about the stressor is reported as related to negative outcomes in mothers of children with autism (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001b). The researchers looked at the relationships between stressors, social support, locus of control, coping style and negative outcomes for 39 mothers and 19 fathers of children with autism. The mean age of the child was 7.47 (SD=3.31) years. Coping was measured with the Ways of Coping Questionnaire (Folkman & Lazarus, 1988). Social support was measured with the Inventory of Socially Supportive Behaviors (Barrea, Sandler, & Ramsay, 1981), which assesses type and amount of the social support received by parents. Measuring social support in terms of type and amount rather than the

usefulness, importance, desirability or in terms of whether or not the support met the expectations of the parent was not assessed in this study.

Hastings et al. (2005) explored the relationships between parental well being and coping strategies. The sample included 89 parents (48 mothers and 41 fathers) of preschool age children and 46 parents (26 mothers and 20 fathers) of school-aged children. Hastings used the COPE inventory (Carver, Scheier, & Weintraub, 1989) to measure coping, the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), to measure parents' health and the parent and family problems subscale of the Questionnaire on Resources and Stress-Friedrich short form (Friedrich et al., 1983) to measure parents' stress. Correlations were computed separately for mothers and fathers between the 4 coping scales and the stress and mental health measures. Hastings found a gender difference related to active avoidance coping and problem-focused coping. He did not find evidence that parental coping varied with the age of the child. Active avoidance coping for both mothers and fathers was associated with more stress and more anxiety and depression symptoms. Religious/denial coping was also associated with depression in mothers and both depression and anxiety in fathers. Positive coping was negatively associated with depression in both mothers and fathers with those parents adopting more positive coping strategies reporting lower levels of depression. It seems that the coping strategy, not gender per se is related to health in his study. However, mothers in this study tended to have the coping styles related to poor health outcomes.

Parental well-being is related to the level of understanding which parents felt that their immediate family member had of their child's problem (Sharpley & Bitsika, 1997). Sharpley and Bitsika surveyed 219 parents of children with ASD to study the influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety and depression. They concluded that family members should be included in behavior management training programs along with the parents and that family members can play a role in parental well-being (Sharpley & Bitsika, 1997). The support within the family continues to be seen in the literature as an important concept to consider as a predictor of parental health and well-being.

The relationship of marital quality and parental well being is presented in Marciano's descriptive study of 42 participants. He found no statistically significant associations between marital quality and social support or marital quality and the severity of the child's autism. However in the qualitative data marital quality in families of children with ASD was defined differently than in other marriages as the child's needs become a component of the parental relationship (Marciano, 2005).

Summary

Based on the review of the literature, the majority of participants in studies involving families of children with ASD are mothers. The overwhelming majority of the literature reviewed reveals that mothers of children with ASD are the primary care-givers and have a high amount of stress. Mothers tend to prefer

emotion-focused support and reach out to other parents of children with ASD for support. They find navigating the amount of printed literature, electronic, and web-based literature overwhelming. Adding to the stress is the disagreement among health care professionals on the best diagnostics and therapies for children with ASD. Couple this with the perception that a quick start for treatments is necessary to reach the best outcomes, and parents soon reach out to those with experience navigating all these circumstances.

Parents are most stressed by the behavior of the children in public that would be more likely with children with more severe forms of ASD. Parents seek emotional, physical and task assistance supports in the day to day life of the child with ASD. The parental relationship is of particular interest here, again, based on review of the literature that revealed the dearth of fathers caring for children with ASD. Mothers traditionally carry a disproportionate burden caring for children with ASD.

Gap

One gap noted in the literature is studies that gather data from both parents of children with ASD. This study examines relationships among stress of parenting, family functioning and HRQL including both parents. A sample that includes fathers of children with ASD would add to the body of research on the concepts of interest.

Hypotheses

- a. High discrepant scores within spouse perceptions of what is and should be in family functioning will be associated with lower HRQL as measured by the Rand 36-Item Health Survey 1.0.
- b. High discrepant scores between spouse views of what is and should be in perceived family functioning will be associated with lower HRQL as measured by Rand 36-Item Health Survey 1.0.

Research Questions

1. What is the influence of one spouse's perceived family functioning as measured by Feetham Family Functioning Survey (FFFS) on the other spouse's perceived family functioning?
2. What is the relationship of parenting stress, family functioning and parental HRQL as measured by the Parenting stress: Autism scale, FFFS and the Rand 36-Item Health Survey 1.0 for parents of children with ASD?
3. Does family functioning mediate the relationship between parental stress and parental HRQL?

Chapter Three: Research Design and Methods

A non-experimental, cross sectional descriptive design was employed in the study. Both parents were asked to fill out questionnaires. The objective of the study was to gain a better understanding of the relationship of parenting stress, family functioning and the health related quality of life (HRQL) for both parents of children with ASD. Selection of the variables in the study was theory-driven. The variables include: parenting stress, family functioning, and HRQL. They were measured using valid and reliable tools.

Sample

Consultation with a statistician revealed that for a dyadic analysis, a sample of 200 couples would be considered adequate, in order to allow for five subjects per variable (Personal communication, P. Simpson, June 12, 2008). No prior study with the same variables for parents of children with ASD was available for reference in terms of a sample size.

Participants were recruited by convenience sampling. Participants volunteered after receiving a research recruitment flyer (see Appendix B), at a conference, at a clinic, via personal email, group e-mail list, list-serv, or posted on social networking sites, or Autism Blogs. The recruitment flyer directed participants to the Internet web site where the consent and the link to the study questionnaires were housed.

Method of Contact (Recruitment)

Places. Participants were recruited via the Internet and in person from several places, locally as well as nationally. In Wisconsin participants were recruited at the following locations: 1) the Autism Society of South Eastern Wisconsin (ASSEW) website January 5, 2009, electronic and paper newsletter February 2009, two parenting series classes, 1 parent support group meeting; 2) The Waukesha County Wisconsin Waiver Program email list December 26, 2008, 3) Autism Transition Training conference of the Wisconsin Cooperative Educational Service Agency (CESA #2), February 15, 2009, as well as the CESA #2 newsletter e-mailed to parents 4) Pediatric Behavioral Health conference, February 20, 2009, Milwaukee; 5) Children's Hospital of Wisconsin neurology, gastro-intestinal and psychiatry clinics, January 2 –March 30, 2009; 6) Easter Seals-Kind care program electronic mail list locally and nationally; 7) Talk about Curing Autism March 2009 parent meeting at Children's Hospital of Wisconsin, and email list; 8) South East Regional Center for Children and Youth with Special Health Care Needs parent resource center located in the main lobby of Children's Hospital of Wisconsin, January 2- March 30, 2009 9) Wisconsin Early Autism Project 10) New Berlin Therapies 11) Autism Society of Wisconsin List-serv; 12) Waisman Center Transition list-serv; and 13) Marquette University News-brief January 15, 2009.

Nationally, participants were recruited from the following locations: 1) email to all the addresses of the local autism societies, and support organizations in the 50 states plus the District of Columbia. I received return e-mail from the

following offices notifying me that the HRRB approved flyer would be made available to parents in the office, at support groups and by email: Los Angeles Asperger Syndrome Parent's Support group; Charlie's gift clinic, Hinsdale IL; Step by Step academy, Worthington OH; Arkansas Autism Resource and Outreach Center via the Autism Treatment Network; Autism Delaware; Center for Autism and Related Disorders (CARD), Gainesville FL; Kane County autism information and support, Kane Co., IL; Panhandle Autism Society; Autism Society of America Inland Empire, CA; 2) Messages on autism-specific pages on web sites a) Autism Speaks: Coping with a child with autism group; Dad's group; b) Face Book: Autism Awareness Group c) Twitter: The Autism Support Network website March 23, 2009; The Autism Community blog February, 2009; d) Meet-up: Autism moms group in Naperville, IL; 3) Via the Organization for Autism Research March 2009 electronic newsletter "The Oracle"; 4) Minnesota school district 287; 5) First Signs Inc. website and 8) The Interactive Autism Network (IAN) Research Database at the Kennedy Krieger Institute and Johns Hopkins Medicine-Baltimore, sponsored by Autism Speaks Foundation.

Data was collected from both parents whenever possible. All data was collected on the Internet. Concerns with the methodology include the equivalence of the questionnaires, the potential sampling bias, and effect on sample size.

Paper and pencil forms were not used in order to keep a uniform data collection method although equivalence between the online and paper and pencil forms of questionnaires has been assessed in past research and found to be the case (Reynolds & Stiles, 2007). In the past, using a web-based survey even with

validated instruments was considered to put a study at risk of sampling limitations, such as reaching people in rural areas (Nardi, 2003). But, web surveys have now become more common place, computers are more powerful, and the ability for people to use them has improved (Dillman, 2007). Collecting data directly from participants into a data base is also becoming more common-place for many conditions. For example, cancer patients have successfully reported symptoms into a web-based interface (Basch et al., 2005). Children with ASD generally like computers so it is likely that parents would own one. Internet service is wide spread, including rural areas, libraries and many public and private businesses offer free wireless internet access.

Careful attention to the design of the e-mailed flyer and the survey placement was done according to principles outlined by Dillman (2007) and by the Human Research Review Board (HRRB) policy on online surveys at Marquette University. Other researchers have published studies where recruitment or data collection via survey monkey (www.surveymonkey.com) took place on the Internet (Clark, 2007; Manning-Walsh, 2004).

Recruiting on the Internet is useful because it is a location where parents of children are likely to see the recruitment flyer. Parents often become isolated due to their child's behavior. They are less likely to be able to leave their child to attend an appointment to participate in research in person than parents of typically developing children. Parents can fill out surveys at their convenience. Internet recruitment and data collection is useful for the large sample needed for this study, as it helps cast a wide net. One negative with web-based surveys is

the reliance on non-personal contact by the investigator to the participants they are recruiting. This may impact recruitment as the direct contact may increase the chance that a person may participate in the study (Reynolds & Stiles, 2007).

Inclusion/Exclusion Criteria

Inclusion criteria for this study consisted of the ability to read English at the 6th grade level, being the biological parent of one or more children, 2-18 years old, with a diagnosis of ASD (Autism, PDD-NOS or Asperger's syndrome), Internet access and residence in the United States, and the ability to identify a spouse or significant other. The term "parent" was not defined in the recruitment flyer. Demographics were collected to describe the sample of participants who self-report as being a parent. Since this was an initial study in which parenting dyads were specifically recruited, data was collected (See Appendix A, Study Enrollment Form) as to the relationship to the child, household members, and the number of children with ASD as a basis for future research.

There were no specific exclusion criteria. The diagnosis of ASD was not confirmed for the study, but rather the parent's report of having a child with ASD was regarded as the inclusion criteria. This decision was based on the fact that there were already 4 lengthy surveys to complete. Adding another survey to confirm diagnosis seemed burdensome.

The participants whose spouse or partners who did not complete the questionnaires, were not excluded from the sample. Feetham (personal

communication, August 20, 2008) recommended looking for differences in the discrepancy scores when only one parent filled out the questionnaires.

Procedure

Approval for the study was obtained from the internal review boards at both Marquette University and Children's Hospital of Wisconsin. Data was collected over the Internet via a web-based site (www.surveymonkey.com) that housed the electronic version of the questionnaires. The researcher's e-mail address was provided in the call for participants as well as log in information to go to the study's on-line web site. The participant read the cover letter and accepted the terms of a consent form and then completed the demographic form and each questionnaire. Confidentiality was maintained. No personal identifiers appeared on the questionnaire. Participants created their own identifier by entering 1) gender 2) month of child's birthday 3) month of spouse's birthday 4) initial of first name 5) State of residence. The consent form wording included text that instructed the participant to ask their spouse to fill out a set of questionnaires. Spouses were matched based on the numeric identifiers.

Instruments

Linkages between the theory concepts, study variables and study measures guided the study design. Instruments were selected to quantitatively measure the concepts in this study (See Table 1).

Study Enrollment Form. A study enrollment form (see Appendix A) was used to capture demographic information and the parent's perception of the child's diagnosis. The form contained parent and child characteristics.

Parent characteristics. Demographic items for parents included number of children, parent age, gender, marital status, race/ethnicity, highest level of education and the length of the parent relationship. Number of children, parent age, and length of parent relationship, were entered as continuous variables. Age was recorded in years. Categories were determined for each of the remaining parent demographic items. Gender was coded as female (1) and male (0). For marital status, participants chose from categories married, single, divorced, separated, widowed, and other. For race/ethnicity parents chose from categories: White, Black, Hispanic, Asian or other. For highest level of education parents chose from the categories: less than 7th grade, junior high, partial high school, high school graduate, partial college, college graduate, or graduate degree.

Table 1 Linkages between Theory Concepts, Study Variables, and Measures

Theory Concept		Stress	Social Support	Quality of Life
1) Stress theory 2) Social Support Theory		1 a) Person: Goals, beliefs about self and the world, personal resources. b) Environment: Harms, threats, challenges, benefits 2) Baseline emotions, behaviors and biology	1) Person-environment relationship (Appraisal and coping) 2) Close relations contribute to a perception support available if needed. Processes operating within relationships matter more than the existence of a relationship.	1) Emotions and their effects. Morale, social functioning, and health. 2) Adherence to health behaviors. Immune response.
Study Variables:	Demographics	Parenting Stress	Family Functioning	Health Related Quality of Life
Study Measures	a. Age of child b. Age of Parent c. Gender of Child d. Gender of Parent e. Marital Status f. Number of adults living in home g. Number of children living in home. h. Parent's education level i. Race j. Age suspected ASD k. Age diagnosed ASD l. Diagnosis	Parental Stressor Scale: Autism	Feetham Family Functioning Survey	Rand 36-Item Health Survey 1.0

Child characteristics. Demographic items for children included age of child, gender, age of suspected diagnosis, age of actual diagnosis, and diagnosis. Age, age of suspected diagnosis, age of actual diagnosis was entered as continuous variables. Age was recorded in years. Gender was coded as female (1) and male (0). The diagnosis of child was dummy coded as there were 3 different possible diagnoses.

Parenting Stress Scale: Autism. Parenting stress was measured with the Parenting Stress Scale: Autism (Appendix C). This 28-item questionnaire captures parental experiences that are stressful or difficult such as behavior and communication, advocating for a child with ASD's needs, parental care giving, and personal and family life (Miles & Phetrasuwan, 2003). Parent responsibilities including basic care giving, socialization, teaching, and protecting the child as well as advocating on behalf of the child are included. There are 4 subscales that represent these responsibilities. The first scale relates to socialization (managing behavior and communication of the child). The behavior and communication subscale includes questions related to the stress of managing the child's behavior in public, helping the child learn how to be with other children, learning how to best communicate with the child, helping the child communicate with others and trying to figure out what their child needs or wants during a tantrum. The second subscale relates to parental care giving (caring, protecting). The care giving scale included questions related to feelings about the child not wanting to be touched, problems related to eating, managing sleep problems, bathing and dressing difficulties, how to discipline the child, overcoming feelings of

protectiveness, keeping life as normal as possible, and keeping the child on a regular routine. The third subscale relates to advocating for the child's needs. The fourth subscale relates to personal and family life. Parents rate the stress they feel on a 1-5 scale where 1 = not stressful, 2 = somewhat stressful, 3 = moderately stressful, 4 = very stressful and 5 = extremely stressful. Responses are summed to form a total score and then calculated into a mean total score, ranging from 0 to 140. Given that there are 28 questions, a mean total scale score greater than 56 would indicate the rating of somewhat stressful. The score of 56 as the indication of 'somewhat stressful' total scale score was determined by multiplying the 28 items by the somewhat stressful score of '2' on the likert scale of 1 to 5. Higher scores indicate higher stress. Phetrasuwan (2003) used the PSS:A in her study of 108 parents of children with ASD. The total scale mean in that study was 75.01 (SD=22.65).

Phetrasuwan (2003) examined the content and face validity of the PSS:A by asking parents and professionals working with children to review the tool and comment on its comprehensiveness, clarity, appropriateness and level of understandability. The instrument was revised based on that input. A principal components factor analysis was done with a sample of 108 (86% Caucasian; 81% married) mothers. Though that study was underpowered for this analysis, 86% of the variance was explained by the four factor solution. The PSS:A correlated $r=0.67$ ($p<.01$) with symptom-related stress, $r=0.61$ ($p<.01$) with depression, and $r=0.25$ ($p<.01$) with Family Satisfaction. In the path analysis, parental stress was significantly related to depression $r=0.56$ ($p<.01$) and

psychological wellbeing $r=-0.44$ ($p<.01$) which provides further support for the construct validity of the PSS:A. The PSS:A was not significantly related to endogenous variables in the path analysis: severity of autism, mother's education, income, child's age or gender. Cronbach's alpha for the entire scale was 0.94. Subscale coefficients were not reported. The means, standard deviations, item/total correlations for the 28 item Parenting Stress Scale: Autism, are shown in Appendix C.

The Parenting Stress Scale: Autism questionnaire, addresses parental coping, using situation and context specific questions. As a process, coping is situation and context specific, so it was important to use the Parenting Stress Scale: Autism to capture the stress and coping in the specific context of parenting for a child with ASD.

Feetham Family Functioning Survey. The Feetham Family Functioning Survey (FFFS) was used to measure family functioning (Feetham & Humenick, 1982) (Appendix D). The first publication using the FFFS was reported in 1984. Since then it has been used in 70 published reports in Japan, USA, UK, South Africa and Australia. Known translations include: Spanish, Russian, Bosnian, Kosovo, Japanese, American Sign Language, Korean, French and Chinese (Feetham et al., 2007).

The FFFS measures the family members' perceptions of family functions. It does not measure the quality of family functions (Feetham, 2008). Feetham defines family functioning as including a commitment to support the functions of the family which include: economic, safety, child rearing, care giving and

communication. Family functioning includes generational relationships, unique sets of rules, priorities and ethics. The family is also considered to be a mediator between the individual and the environment. The family is affected by cultural patterns. Multiple forms of families occur in western countries (Feetham et al., 2007). The FFFS measures the family's response to a child with a chronic health condition and also to normal children. The tool consists of 25 items, and is designed to be self-administered in approximately 10 minutes (Roberts & Feetham, 1982). Three major family functions are assessed: 1) relationship between the family and broader social units, such as schools and work outside the home; 2) relationships between the family and its subsystems, such as the division of labor; 3) relationships between the family and the individual, focusing on the reciprocal relationships between husband and wife and between parents and children (Roberts & Feetham, 1982).

Each item includes a stem item, followed by three questions: a) how much there is and b) how much there should be c) how important is this to you? An example of an item is: "The amount of time you spend with your spouse/partner. Each item has seven response options; where 1 represents 'little' and 7 represent 'much'. There are also two open ended questions "What is most difficult for you now?" and "What is most helpful to you now?" The format of the questions is based on a system used by Lyman Porter (1963). Porter studied job attitudes in management. He found that there was a discrepancy between the need for fulfillment and importance of several types of psychological needs associated with line versus staff types of management jobs (Porter, 1963).

Feetham (2007) reported the scoring for the FFFS is as follows: First the discrepancy score is determined for each item. This is the difference between each A and B score for each item. This is converted to an absolute score. Next, the discrepant scores from each item are summed for an instrument score. The total family functioning instrument discrepancy score can range from a possible score of 0 to 126. The family functioning instrument scores tend to range from 17 – 35 (Feetham et al., 2007). The next step is to sum the total instrument score for each respondent and determine the mean instrument score for all respondents. This is determined by dividing the sum by the number of respondents. A high score indicates a higher discrepancy between the responses expectation of what is from their perception of what should be. The importance score is not included in the instrument score (Feetham, 2008).

In this study, to examine Hypothesis A and B, the discrepancy score a-b ('what is '-'what should be') was used. The scoring system allows the evaluation of individual dissonance or dissatisfaction among or within the three major areas of family relationships (Roberts & Feetham, 1982). A higher score indicates higher discrepancy between desired and present functioning. Cronbach alpha reliability coefficient is reported as 0.81. Stability (test-re-test at 2 weeks) was $r=0.85$ for 22 mothers (Roberts & Feetham 1982). Content validity includes previous use in literature, clinical observations, experts and parents who discussed the instrument with the developers. Concurrent validity includes the correlation coefficient between the FFFS and the Family Functioning Inventory (FFI) for 103 mothers $r=0.54$ ($p<.001$). Construct validity includes factor analysis

supports the 3 areas of family functioning as relationships (Roberts & Feetham, 1982).

Rand 36-Item Health Survey (Version 1.0). The Rand 36-Item Health Survey (Version 1.0) was used to measure health related quality of life (Appendix E). HQRL is one measure of quality of life. It refers to the effects of health, illness and treatment on quality of life (Ferrans et al., 2005). These include biological function, symptoms, functional status, and general health perceptions (Ferrans et al., 2005). HRQL includes the effects of individual characteristics and environmental characteristics on biological function.

There are a total of 36 items that cover eight health concepts. These include: physical functioning (10 items, Cronbach's alpha=0.93), bodily pain (2 items, Cronbach's alpha= 0.78), role limitations due to health problems (4 items, Cronbach's alpha= 0.83), role limitations due to personal or emotional problems (3 items, Cronbach's alpha= 0.83), emotional well being (5 items, Cronbach's alpha= 0.90), social functioning (2 items, Cronbach's alpha= 0.85), energy/fatigue(4 items, Cronbach's alpha= 0.86), general health perceptions (5 items, Cronbach's alpha= 0.78), and a single item that provides an indication of perceived health.

The 36 items were adapted from longer instruments completed by patients participating in the Medical Outcomes Study (N=2471), an observational study in physician practices styles and patient outcomes in different health care delivery (Stewart, Sherburne, Hays, & Ware, 1992). Eight separate scores are calculated. Most of the questions are rated on a Likert scale. Scales range from 3 to 6

points. Some questions are yes/no. All questions are recoded to 0-100 percent representations according to a scoring guide that comes with the tool (see appendix E).

Psychometric qualities of the RAND 36 –item Health Survey Version 1.0 were investigated in a study of 1, 063 adult inhabitants of a Dutch township (VanderZee, Sanderman, Heyink, & deHaes, 1996). The internal consistency of the instrument was high suggesting high convergent validity. A multitrait-multimethod matrix revealed that the RAND-36 scales showed higher correlations with corresponding scales from other instruments than with non-corresponding scales. Multivariate analysis of variance (MANOVA) showed significant effects of age for physical functioning, role limitation (physical problem), general health perception and pain, and significant effects of age for physical functioning and general health perception. The only significant gender difference was for mental health. For the 33-47 year old age group the means and standard deviations for the 8 subscales were as follows: physical functioning 87.6 (17.7), bodily pain 87.1 (19.6), role limitations due to health problems 82.3 (31.8), role limitations due to personal or emotional problems 82.4 (33.6), emotional well being 75.8 (18.5 items), social functioning 66.9 (18.5), energy/fatigue 82.7 (23.9), general health perceptions 73.5 (20.4) (VanderZee et al.).

An additional scoring technique for the instrument yields two scores: the physical component score (PCS) and the mental component score (MCS). The 8 subscale scores are standardized according to the formulas in the user's manual.

The scoring allows for an assessment of overall physical and mental status. Psychometrically based summary measures aggregate the eight concepts with different weights to two components, the PCS and the MCS, without substantial loss of information (Ware, Kosinski, & Keller, 1994). The mean scores for both the PCS and the MCS of the general U.S. population are 50 with a standard deviation of 10 (Ware et al., 1994).

Data Management

Overview. Participants completed the questionnaires at the www.surveymonkey.com website. As the data were entered by the participant it automatically was entered into an Excel spread sheet. The Excel file was imported to SPSS 16.0 (SPSS, 2008) by a statistician with the Children's Research Institute. Each participant had the opportunity to fill out four surveys. Each survey began with the same seven questions for matching purposes, for identification of the dyads, while allowing for anonymity. The questions included: gender, birth month of oldest child with ASD, month of your birthday, month of your spouse/partner's birthday, initial of your first given name, initial of your spouse/partner's first given name and the state you currently live in. Dyads were identified visually by the statistician by looking at the data set for the 7 matches. Participants who completed all four surveys were given a group=4 code. Dyads in the group = 4 group were used for the dyad data analysis.

Checks for agreement between husband and wife were performed on gender of their child, age of diagnosis, and the diagnosis. Gender of the child did

not match in one case. Diagnosis of child differed in one case. Age of diagnosis differed in 5 cases. Therefore in the regression we used the females' viewpoint.

Missing data. There were four surveys: Demographic survey, Parenting Stress: Autism, FFFS and the Rand 36-Item Health Survey (Version 1.0). The number of respondents who completed all aspects of each survey was 418, 387, 370, and 367, respectively (Figure 2). While 418 participants started filling out surveys, only 367 completed all four surveys. In addition, each of the four surveys had missing data. For the demographic survey 8 of the 426 participants only answered the first seven questions intended for matching the surveys. These 8 were deleted. For the remaining 3 surveys, the Parenting Stress: Autism survey, the FFFS and the Rand 36 item Health Survey version 1.0, some participants only answered the demographic questions used for matching and/or the first few questions and none of the remaining questions. These cases were deleted. Across the 3 surveys, 23 (6.3%) of the cases were deleted for a total of 367 participants. For any one question the most missing were 5 responses which is acceptable.

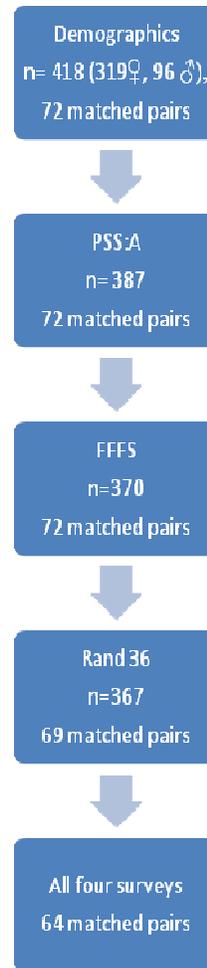


Figure 2. Missing Data

The reason for participants filling out only some of the surveys and then stopping is not known. Possibilities include the length of the surveys and the resultant time commitment to fill out the forms. The demographic information was the first survey that participants filled out. In retrospect this is a limitation in the design of the survey placement. Dillman (2007) recommends placing the demographic survey as the final survey. Another limitation was the need for the participant to fill out the seven demographic matching questions four times total. The seven questions were placed in front of each of the survey questionnaires. The decision was made to place each survey as a separate link so that the

participant would have the option of completing the surveys in more than one session. However, the repetition of the 7 questions may have frustrated participants and led to missing data.

Data quality. Participants were instructed to complete the survey for themselves, not on behalf of someone else. They were also asked to complete the survey only once. Visual inspection of the data for quality was performed for visual patterns of contradictory responses. No cases were found with contradictory responses.

Data analysis. Descriptive statistics (medians, means, standard deviations, and ranges) were used in analyzing demographic data for the total sample and the dyads for demographic characteristics and the severity of Autism. In addition, descriptive statistics (medians, means, standard deviations, and ranges) were performed for each scale or survey. Variables included and analyzed are summarized in Table 2. Specifics will be provided in the text. The hypotheses and research questions are presented next.

Hypothesis A. High discrepant scores within spouse perceptions in what is and should be in family functioning will be associated with lower HRQL. To examine this question, the FFFS a) what is score minus the b) what it should be score was computed for each item (D score). The D score was examined with the dependent variables, the physical health component (PCS) and the mental health component (MCS) of the Rand-36 item Health Inventory version 1.0. using Pearson's r for both fathers and mothers separately.

Hypothesis B. High discrepant scores for spouse views on perceived family functioning will be associated with lower HRQL. For this analysis a discrepancies score (D score) was calculated for the items on the FFFS. The D score is equal to the a) 'what is score' minus the b) 'how much there should be' score. The D score was computed for each item. A total similarity score was to be computed for each parent dyad. This is what Kenny, Kashy and Cook (2006) termed an idiographic dyadic analysis in which a dyadic index score is created. Since Feetham (2007) recommended using the total survey rather than subscales of the FFFS, the total scale was to be used for creation of the dyadic index. Since similarity in distributional shape, as well as the spread and level of difference all are of interest in this hypothesis, the interclass correlation was to be used, rather than a correlation coefficient, covariance, or a regression where mother's scores were used to predict father's scores - or vice versa (Kenny et al., 2006). The variance was thought to be indicative of how much couples differ. The interclass correlation dyadic index was to be analyzed with Pearson's r to examine whether highly discrepant spouse views are associated with lower HRQL for either partner. However, the sample of 64 dyads was not large enough to do the analysis. It was determined by the statistician that a Wilcoxon Signed Ranks Test should be performed to detect differences between the 2 related groups (males and females).

Question 1. What is the influence of one spouse's perceived family functioning as measured by Feetham Family Functioning Survey (FFFS) on the other spouse's perceived family functioning? Relationship, rather than influence,

was determined with a Pearson's r . Correlations were examined between parents' total scores – the discrepancy between a) how much there is and b) how much there should be, of the three areas of family relationships. Feetham (2007) recommended use of the total score, rather than subscales in analyses. As per Feetham (2007), Feetham, Perkins and Carroll's (1993) recommendations, means were compared for fathers and mothers, and the distributions examined for outliers as well as the shape of the distribution of the scores. Further analysis was guided by examination of these data as to whether a paired couple score should reasonably be computed and entered into the analysis.

Question 2. What is the relationship of parenting stress, family functioning, and HRQL for parents of children with Autism Spectrum Disorder? Pearson r correlations were used to examine simple correlations among total scores for the entire sample (both parents separately and paired) regarding parenting stress, family functioning support (a) 'How much there is' – 'How much there should be' (D score) (Feetham, 2007) and parental HRQL (physical and mental, separate). Significant correlations were used in further analyses. Structural equation modeling was attempted but not successful (Simpson, 2009). Stepwise linear regression was used to develop models. Backwards linear regression was done as a check.

Question 3. Does family functioning (FFFS) (a) 'How much there is' – 'How much there should be' (D score) mediate the relation between parental stress (PSS:A) and parental HRQL?



Linear regression was used to determine whether or not family functioning mediated the relation between parental stress variables and the physical health component (PCS) and the mental health component (MCS) of the Rand-36 item Health Inventory version 1.0. HRQL. This allowed for a more precise description of the relationship of parenting stress and HRQL. A mediator effect is only tested when there is a significant direct effect between the independent variable and the outcome variable (Bennett, 2000). A mediator is a variable that specifies how the association occurs between the independent variable, parenting stress and the outcome variable, parental HRQL. The linear regressions were initially run separately for mothers and fathers. The dependent variables were the physical health component (PCS) and the mental health component (MCS) of the Rand-36 item Health Inventory version 1.0. Collinearity diagnostics were run for all variables and corrections made when needed. 1) The four subscales of the PSS:A were entered first to see if there was a direct relationship. 2) FFFS discrepancy scores (D scores) were entered next to see if there was a relationship of any of the 4 parenting stress variables on D score of the FFFS. If relationships specified in 2 areas were significant and if any relationship between parenting stress and HRQL was significant in step 2, then a mediating effect of family functioning between parenting stress and HRQL was supported.

Table 2 Variables included and analyzed

<u>Question</u>	<u>Instrumentation</u>	<u>Analyses</u>
Internal consistency Descriptives	a. PSS:A b. FFFS c. Rand 36	Cronbach alpha Descriptives
Description of the sample	Study enrollment form	SPSS descriptives
Hypotheses: A. High discrepant scores within spouse perceptions of what is and should be FFFS will be associated with lower HRQL. B. High discrepant scores between spouse perceptions of what is and should be FFFS will be associated with lower HRQL. 1. What is the influence of one spouse's perceived FFFS on the other spouse's perceived FFFS? 2. What is the relationship of parenting stress, family functioning, and HRQL for parents of children with Autism Spectrum Disorder?	FFFS Rand 36	A. A discrepancy variable (D score) was computed for males and females. The a-b is the discrepancy score D. The absolute of the D score was analyzed was analyzed in comparison to Rand 36 using Pearson's r. B. The absolute of the D score was used. It was not possible to conduct structural equation modeling given the sample recruited. Instead a Wilcoxon Signed Ranks Test was performed to detect differences between the 2 related groups (males and females). 1. A discrepancy variable (D score) was computed for males and females. Pearson's r correlation was analyzed
	PSS:A FFFS Rand 36	2. Computed stepwise linear regression. Backward linear regression was done as a check. (Demographics, parental stress and FFFS as independent variables, and HRQL as dependent variables).
3. Does family functioning mediate the relation between parental stress and parental HRQL?	FFFS Rand SF 36	3. Linear Regression.

Human Subjects Protection

Human Research Review Board approval was obtained from Children's Hospital of Wisconsin and Marquette University. Informed consent was obtained. Subjects were allowed to withdraw from participation at any time. All information revealed in this study will be kept confidential. All data was assigned an arbitrary code number rather than using participants' names (which were never collected) or other information that could identify the participant as an individual. When the results of the study are published, the participants will not be identified by name. Personal information may be disclosed if required by law. Also, scientific data from this study will be presented at meetings and published so that it may be useful to others, as long as it is not identifiable with the participant.

Chapter Four: Results

The purpose of the study was to gain a better understanding regarding the relationship of parenting stress, family functioning and the health related quality of life (HRQL) for both parents of children with ASD. Demographics were collected along with data on three surveys: 1) Parenting Stress: Autism, 2) Feetham Family Functioning Survey and 3) Rand 36-Item Health Survey (Version 1.0).

The number of respondents who completed all aspects of each survey was 418, 387, 370, and 367, respectively. Of the 367 respondents, 64 male and female parent dyads were identified. Participants represented forty-six of the fifty states of the USA. The majority of the participants were from Wisconsin (n=96, 23%), followed by Pennsylvania (n=23, 6%), New York (n=21, 5%), New Jersey (n=19, 5%), Florida (n=19, 5%), Illinois (n=18, 4%), Texas (n=17, 4%), Virginia (n=13, 3%), California (n=12, 3%), Ohio (n=11, 3%), and Minnesota (n=10, 2%). Other states ranged from 1 to 8 participants. Missing States were: Alaska, Hawaii, South Dakota, and Alabama. Data was collected over a period of 3 months.

The study was closed after there was no participation for 2 days and only 10 participants for the previous 10 days. Although 200 dyads were considered to be the required number for the research questions, it was determined that the maximum number of voluntary participants for the study, as designed, was reached.

Participant Description

The Parents. Of the 418 respondents who completed questionnaires (Table 3), 319 (77%) were female, and 96 (23%) were male. The mean age of the parents was 40 (SD=7.3) years. Most participants (N=351, 85%) were married, white (N=374, 92%), college educated (N=365, 87%), with a professional occupation (N=325, 78%). The median length of time in the relationship with the partner was 14 years (7.9 %, range 0-39 years). The mean number of children living at home full or part time was 2.2 (SD 0.9). For the 64 male and female dyads, (see Table 4) males mean age was 42 (SD=7.8) years while females was 39.2 (SD=7.2) years. Most (N=60, 94%) were married, white (N=60, 95%), and in a relationship with the spouse for a mean of 14.2 (SD=5.8) years. The mean number of children living in the home full or part time was 2.2 (SD 0.8).

The Children. Most of the children (N=330, 81%) were boys. Ages ranged from 2 years to 31 years, with a mean age of 8.8 (SD=4.6). The age of diagnosis ranged from 1 years to 18 years, with the mean age of diagnosis being 4.1 years (SD=2.8). However, most of the parents reported suspecting their child had ASD at the mean age of 2.8 years (SD=2.3). Parents (Ware et al., 1994) primarily reported a diagnosis of autism (N=227, 56%) followed by PDD-NOS (N=96, 23%) and Aspergers (N=86, 21%).

Children of the 64 male and female dyads, consisted of mainly boys (N=53, 83%), with a diagnosis of autism (N=39, 62%), ranging in age from 2-24 years with a mean age of 7.8 (SD=3.9) years. The age of diagnosis ranged from

1 year to 16 years, with the mean age of diagnosis being 3.7 years (SD=2.7). However, most of the male parents reported suspecting their child had ASD at the mean age of 2.9 years (SD=2.3) and most females parents at 2.6 years (SD=1.9).

Scale Statistics

Cronbach's alpha analysis was performed for the three scales used in the study (Table 5). This statistic is used to detect the internal consistency reliability of the questionnaires. All the questionnaires used in the study had acceptable internal reliability as shown in Table 5.

Table 3 Summary of Parent and Child Demographics (N= 418)

	N Eval	N, (%)
Parent gender, N (%)	415	
Female		319 (77)
Male		96 (23)
Parent age, years	410	
Mean \pm SD		40 \pm 7.3
Median (range)		39 (23-69)
Marital Status, N (%)	413	
Married		351 (85)
Divorced		30 (7)
Separated		12 (3)
Single		12 (3)
Widowed		2 (1)
Other		6 (2)
Relationship length, years	391	
Mean \pm SD		14.6 \pm 6.5
Median (range)		14 (0-39)
Number of children (full or part time)	391	
Mean \pm SD		2.2 \pm 0.9
Median (range)		2 (1-7)
Parent race/ethnicity, N (%)	405	
White		374 (93)
Hispanic		18 (4)
Black		4 (1)
Asian		3 (1)
Other		6 (1)
Parent education, N (%)	411	
Less than High School		3 (1)
High School Graduate		43 (11)
Partial College		105 (26)
College Degree		158 (38)
Graduate Degree		102 (25)
Parent occupation, N (%)	414	
Professional		325 (78)
Full-time Parent		66 (16)
Trade		17 (4)
Student		6 (2)
Gender of 1 st child with autism, N (%)	409	
Female		79 (19)
Male		330 (81)

Table 3. Continued	N Eval	N, (%)
Current age of 1 st child with autism, years, N (%)	410	
Mean \pm SD		8.8 \pm 4.6
Median (range)		8 (2-31)
Age parent first suspect autism diagnosis, years	409	
Mean \pm SD		2.3 \pm 2.3
Median (range)		2 (1-16)
Age of diagnosis for 1 st child with autism, years	406	
Mean \pm SD		4.1 \pm 2.8
Median (range)		3 (1-18)
Diagnosis of 1 st child, N (%)	409	
Autism		227 (56)
PDD-NOS		96 (23)
Asperger's		86 (21)

Table 4 Summary of Parent and Child Demographics (N= 128)

	<u>N Eval</u>	<u>N, (%)</u>
Parent gender, N (%)	128	
Female		64 (50)
Male		64 (50)
Parent age, years		
Female	64	
Mean \pm SD		39.2 \pm 7.2
Median (range)		38 (25-64)
Male	63	
Mean \pm SD		42.0 \pm 7.8
Median (range)		41 (29-69)
Marital Status, N (%)		
Female	64	
Married		61 (95)
Divorced		2 (3)
Single		1 (2)
Male	64	
Married		60 (94)
Divorced		4 (6)
Single		--
Number of children (full or part time)		
Female	63	
Mean \pm SD		2.2 \pm 0.8
Median (range)		2 (1-5)
Male	61	
Mean \pm SD		2.2 \pm 0.8
Median (range)		2 (1-5)
Relationship length, years	128	
Mean \pm SD		14.3 \pm 5.8
Median (range)		14 (2-31)
Parent race/ethnicity, N (%)		
Female	64	
White		60 (95)
Black		--
Hispanic		1 (2)
Mixed		2 (3)
Male	63	
White		60 (95)
Black		1 (2)
Hispanic		2 (3)
Mixed		--
Current age of 1 st child with autism, years, N (%)	64	
Mean \pm SD		7.8 \pm 3.9
Median (range)		8 (2-24)

Table 4. Continued	N Eval	N, (%)
Age parent first suspect autism diagnosis, years	64	
Female		
Mean \pm SD		2.6 \pm 1.9
Median (range)		2 (1-11)
Male	64	
Mean \pm SD		2.9 \pm 2.3
Median (range)		1 (1-15)
Age of diagnosis for 1 st child with autism	64	
Female		
Mean \pm SD		3.7 \pm 2.7
Median (range)		3 (1-16)
Male	63	
Mean \pm SD		3.7 \pm 2.7
Median (range)		3 (1-16)
Diagnosis of 1 st child, N (%)**	63	
Autism		39 (62)
PDD-NOS		13 (21)
Asperger's		11 (17)

**used female responses

Table 5 Cronbach's Alpha for 3 Surveys

Survey	Cronbach's Alpha Dyads Only (N=128)	Cronbach's Alpha Full sample
Parenting Stress: Autism		
Male	.96 (N=61)	.95 (N= 94)
Female	.94 (N=59)	.95 (N=257)
Feetham Family Functioning Survey		
Male	.91	.91 (N= 29)
Female	.90	.91 (N=210)
Rand 36-Item Heath Survey 1.0		
Male	.78	.89 (N= 26)
Female	.78	.94 (N=212)
Physical Functioning subscale		
Male	.93	
Female	.93	
Role limitation (physical) subscale		
Male	.87	
Female	.86	
Role limitation (emotional) subscale		
Male	.83	
Female	.83	
Energy/fatigue subscale		
Male	.90	
Female	.88	
Emotional Well-being subscale		
Male	.83	
Female	.87	
Social Functioning subscale		
Male	.82	
Female	.87	
Pain subscale		
Male	.87	
Female	.91	
General Health subscale		
Male	.81	
Female	.86	

Analysis

The model (Figure 1) postulates nine exogenous variables (age of child, age of parent, gender of child, diagnosis of child, number of children living in the home, marital status, length of parent relationship, age parent suspected ASD, and age diagnosed with ASD) and seven endogenous variables [four subscales for parenting stress, family functioning discrepancy score (D score), physical health component (PCS) and mental health components (MCS) of HRQL]. The total discrepancy score (D score) between 'how much there is now' and 'how much there should' for the 25-item FFFS questionnaire was postulated to mediate the path from the four subscales of the Parenting Stress: Autism (PSS:A) to the dependent variables the physical and mental health components of the Rand 36 item Health Inventory Version 1.0 (PCS and MCS) .

Overall, parents reported somewhat to moderate amounts of parenting stress, a high discrepancy score for 'how much there is now' and 'how much there should' family functioning, low levels on the mental health and energy/fatigue as measured by subscales of the HRQL, and high average scores on the physical health subscales of the Rand 36 item Health Inventory Version 1.0.

Descriptives for the study variables are presented next, followed by results of the analysis for each research question. Finally, a model with demographic variables will be presented.

Stress. On the PSS:A the total scale mean was 71.18 (SD=25.7) for men and 83.27 (SD=24.97) for the women (Table 6). The highest levels of stress were reported on the items in the behavior and communication subscales for both men and women.

Family Functioning. The total mean discrepancy score for the FFFS (Table 7) was 33.06 (SD= 20.11) for men and 41.97 (SD=21.14) for women. The mean importance score for men/women respectively was 117.84 (SD=23.57) and 131.58 (SD=22.33).

HRQL. The average sub-scale scores for the Rand 36-Item Health Survey 1.0 are shown in Table 8. The highest average scores were on the male physical functioning subscale (88.59) and the female physical functioning subscale (80.62). The physical health component score (PCS) and the mental health component score (MCS) of the Rand SF 36 version 1.0 are shown in Table 9.

Table 6 Summary of Parental Stressor Scale: Autism Statistics

	Number of items*	Average	Mean	Median	SD	Min-Max
Male (N)						
Total scale (61)	28	2.54	71.18	64.00	25.70	25-130
Subscales						
Behavior and Communication (64)	6	2.95	17.78	18.00	5.54	6-29
Advocating for Needs (63)	4	2.62	9.73	10.00	4.09	0-19
Parental Care giving (63)	8	2.29	18.16	18.00	7.67	5-37
Personal and Family life (62)	10	2.57	25.74	24.00	11.68	0-49
Female (N)						
Total scale (59)	28	2.97	83.27	85.00	24.97	20-137
Subscales						
Behavior and Communication (62)	6	3.3	19.95	20.00	5.34	6-30
Advocating for Needs (64)	4	2.97	11.88	12.00	4.41	4-20
Parental Care giving (63)	8	2.52	20.19	20.00	7.85	5-40
Personal and Family life (62)	10	3.17	31.71	34.00	11.12	5-49

*items scored 0-5 (0=not applicable, 1= not stressful, 2=somewhat stressful, 3=moderately stressful, 4=very stressful, 5= extremely stressful)

Table 7 Summary of Feetham Family Functioning Survey Statistics

	Number of items*	Mean	Median	SD	Min-Max
Male (N=64)					
Total scale C score	25	117.84	119.00	23.57	50-168
Total D score (A-B)		33.06	31.50	20.11	0-94
Female (N=64)					
Total scale C score	25	131.58	133.50	22.33	71-174
Total D score (A-B)		41.97	42.50	21.14	2-95

*items scored 1-7 (1= Little, 7 = Much).

Table 8 Summary of Rand 36-Item Health Survey 1.0 statistics

	Number of items*	Average	Mean	Median	SD	Min-Max
Male (N=64) Subscales						
Physical Functioning	10	88.59	885.94	950.00	207.1	100-1000
Role limitation due to physical health	4	82.45	329.69	400.00	129.32	0-400
Role limitation due to emotional problems	3	68.75	206.25	300.00	119.36	0-300
Energy/fatigue	4	41.95	167.82	160.00	87.77	0-360
Emotional Well-being	5	63.19	315.94	340.00	102.86	80-480
Social Functioning	2	71.88	143.75	150.00	55.46	0-200
Pain	2	73.36	146.72	157.50	48.00	0-200
General Health	5	61.38	306.64	325.00	104.58	25-500
Female (N=64) Subscales						
Physical Functioning	10	80.62	806.25	900.00	249.68	50-1000
Role limitation due to physical health	4	51.58	260.32	300.00	157.13	0-400
Role limitation due to emotional problems	3	41.29	123.87	100.00	125.34	0-300
Energy/fatigue	4	33.28	133.13	110.00	94.03	0-340
Emotional Well-being	5	50.56	252.81	250.00	109.97	20-460
Social Functioning	2	61.14	122.27	112.50	57.41	0-200
Pain	2	65.86	131.72	135.00	57.32	0-200
General Health	5	52.97	264.84	250.00	122.53	50-475

Table 9 PCS and MCS components of Rand 36-Item Health Survey 1.0

	Mean	Median	SD	Min-Max
Male (N=61)				
PCS	51.16	54.18	9.56	20.50 - 65.10
MCS	41.60	45.30	12.93	8.20 - 62.30
Female (N=59)				
PCS	49.10	51.88	11.22	23.30 - 69.80
MCS	34.21	33.50	13.11	6.00 - 58.90

Hypotheses

Hypothesis A. High discrepant scores within spouse views of what is and should be in perceived family functioning will be associated with lower HRQL as measured by Rand 36-Item Health Survey 1.0. Hypotheses A was partially supported as shown in Table 10. Using Pearson's r , males' D scores correlated $-.55$ ($p < .01$) with their MCS, but did not correlate significantly with PCS. Females' D scores correlated $-.58$ ($p < .01$) with their MCS and $-.37$ ($p < .01$) with their PCS.

Hypothesis B. High discrepant scores between spouse views of what is and should be in perceived family functioning will be associated with lower HRQL as measured by Rand 36-Item Health Survey 1.0. A Wilcoxon Signed Ranks Test was performed (Table 10) to detect differences between the 2 related groups (males and females). For the FFFS there was a significant difference ($Z = -3.12$, $p = 0.002$) for the discrepancy scores on the FFFS comparing males and females. Females had wider discrepancy scores than males.

A structural equation model analysis was planned, but was not possible given the sample recruited. The statistician determined that a Wilcoxon Signed Ranks Test should be performed to detect differences between the two parents. Results are shown in Table 11.

Question 1. What is the influence of one spouse's perceived family functioning as measured by the FFFS on the other spouse's perceived family functioning? Relationship, rather than influence was determined with a Pearson's r between the absolute of the parents' discrepancy 'D' scores. The D score was calculated by subtracting b) how much there should be from a) how much there is now. As shown in Table 10 male and female D scores correlated .44 ($p < .01$).

Question 2. What is the relationship of parenting stress, family functioning and HRQL for parents of children with ASD? First, Pearson's r was run on the aggregate sample of 128 participants. Next, the data on male and female D scores were analyzed separately. Results for the correlations of all four subscales of the PSS:A along with the diagnosis of the child, the total female D score, and the total male D score are presented in Table 12. The total female D score correlated with all 4 parenting stress subscale scores ($p < .01$) indicating more stress with higher discrepancy scores. The total male D score correlated with higher stress for personal life, behavior and communication ($p < .01$), as well as advocating and care-giving ($p < .05$).

Pearson's r was run on all four subscales of the PSS:A, the total female D score, the total male D score, the PCS male, PCS female, MCS male, and the

Table 10 Correlational Analysis of all Key Variables for Males and Females in Hypothesized Model

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Stress Advocate Male	1													
2. Stress Advocate Female	.32*	1												
3. Stress B/C Male	.60**	.23	1											
4. Stress B/C Female	.34**	.68**	.43**	1										
5. Stress Care give Male	.52**	.27*	.74**	.39**	1									
6. Stress Care give Female	.21	.70**	.27*	.66**	.45**	1								
7. Stress PL Male	.60**	.20	.74**	.32*	.76**	.34**	1							
8. Stress PL Female	.39**	.69**	.32*	.65**	.41**	.76**	.45**	1						
9. Total Male D Score	.29*	.10	.49**	.25	.29*	.14	.49**	.21	1					
10. Total Female D Score	.34**	.58**	.50**	.57**	.49**	.57**	.50**	.70**	.44**	1				
11. MCS Male	-.23	-.20	-.25	-.07	-.32*	-.03	-.38**	-.21	-.55**	-.27*	1			
12. MCS Female	-.17	-.42**	-.25	-.34*	-.21	-.48**	-.28*	-.52**	-.52**	-.58**	.31*	1		
13. PCS Male	.12	.06	.00	.22	.18	.24	.15	.27*	-.19	.08	-.13	-.14	1	
14. PCS Female	-.11	-.41**	-.01	-.36**	-.03	-.41**	-.00	-.30*	-.05	-.37**	-.26	.12	-.00	1

* Correlation is significant at the 0.05 level 2-tailed; ** Correlation is significant at the 0.01 level 2-tailed.

B/C = Behavior and communication, PL= Personal Life

MCS= Mental health component of the Rand 36 item Health Inventory Version 1.0, PCS= Physical health component of the Rand 36 item Health Inventory Version 1.0

Table 11 Wilcoxon Signed Rank Test –FFFS: Total Discrepancy Score – Comparing Males and Females

Total Female D score -Total Male D Score	N	Mean Rank	Sum of Ranks
Negative ranks	18(a)	29.5	531.00
Positive ranks	44(b)	32.32	1422.00
Ties	2(c)		
Total	64		

a Total Female D Score < Total Male D score

b Total Female D Score > Total Male D score

c Total Female D Score = Total Male D score

MCS female (Table 10). The MCS male and the MCS female were related ($r=.31$, $p=.05$). This indicates that the mental health of the male and female in the parenting dyad were positively related. The PCS male and PCS female were not related.

All of the 4 stress variables were related for the male-female dyads: advocating for child's needs ($r=.32$, $p=.05$), behavior and communication ($r=.43$, $p=.01$), parental care giving ($r=.39$, $p=.01$), and personal and family life ($r=.45$, $p=.01$). Males and females rated the amount of stress for the child they are parenting, similarly. The D scores for males and females were also related ($r=.44$, $p=.01$). This indicates that when one parent had a wide discrepancy in expectations about family functioning the other parent did as well.

The D score for females was related to all variables except for male PCS. This indicates that for females the discrepancy between 'how much there is now'

and 'how much there should be' for family functioning was related to both stress and their mental and physical health, along with the males' stress and mental health.

The D score for males was related to all variables except the stress of advocating for the child's needs and the PCS male. This indicates that the discrepancy between 'how much there is now' and 'how much there should be' for family functioning was related to three of the four stress subscales and the mental health components of the HRQL measure (Rand 36 Health Inventory Version 1.0).

The MCS was generally negatively related to the stress variables and D scores. As stress and the D score increase, MCs and PCS of the HRQL decrease. The stress variables were all positively related to each other and the D score.

Additional correlations were run on demographics and subscales of the PSS:A (Table 11). The stress subscales were related to each other. The stress of care-giving and the stress of behavior and communication were related to the gender of the child ($p=.05$).

Table 12 Correlational Analysis of Key Variables

Variable	1	2	3	4	5	6	7	8	9	10
1. Age of child	1									
2. Age of parent	.47**	1								
3. Gender of child	-.19*	-.14	1							
4. Length of relationship	.66**	.53**	-.23**	1						
5. Age suspected	.59**	.28**	-.06	.42**	1					
6. Age diagnosed	.68**	.33**	-.11	.49**	.84**	1				
7. Stress (personal life)	-.03	.11	.18	.03	.09	.16	1			
8. Stress (care-giving)	-.03	.08	-.21*	.00	.05	.06	.76**	1		
9. Stress (advocating)	.03	.05	.13	-.06	.13	.18*	.67**	.63**	1	
10. Stress (Behavior and communication)	-.03	.13	.18*	.01	.03	.09	.71**	.71**	.65**	1

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the .05 level (2-tailed).

Table 13 Correlational Analysis of Key Variables

Variable	1	2	3	4	5	6	7
1. Diagnosis of child	1						
2. Stress (advocating)	.15	1					
3. Stress (personal life)	.21*	.67**	1				
4. Stress (care-giving)	.10	.63**	.76**	1			
5. Stress (behavior and communication)	.15	.65	.71**	.71**	1		
6. Total Female D score	.12	.34**	.50**	.49**	.50**	1	
7. Total Male D score	.01	.29*	.49**	.29*	.49**	.44**	1

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the .05 level (2-tailed).

Question 3. Does family functioning (FFFS) ‘how much there is’ –‘how much there should be’ (D score) mediate the relation between parental stress (PSS:A) and parental HRQL? For this question, the mental health component score (MCS) and the physical health component score (PCS) of the Rand 36 Health Inventory Version 1.0 (HRQL measure), were considered separately in determining the mediation effect of the D score. The 4 subscales of the PSS:A (personal life, care-giving, advocating, and behavior and communication) were also considered separately.

To investigate the mediating effect of the D score, the MCS and the PCS were regressed on the four stress parameters and gender only, on the D score only and then on the stress, gender and D scores. If the effect of the stress parameters decreased, the D score would be considered a mediator for the stress effect on the HRQL (PCS, and MCS). In fact, it would imply that the stress parameter affects the D score.

Results of the regressions for male PCS and MCS are found in Table 14. Results of the regressions for female PCS and MCS are found in Table 15.

For the PCS for males, the stress subscale of personal life/family life was the only statistically significant variable ($p=.03$) (Table 14, Model 1). For females, the stress of care-giving was the only significant variable impacting physical health ($p<.001$) (Table 15, Model 1).

When considering the MCS, the discrepancy in ‘how much there is’ – ‘how much there should be’ in family functioning as measured by the D score mediated the effect of the stress of personal and family life for both genders

($p < .001$). However, for females, it was only the D score that is significant ($p < .001$) (Table 15, Model 3), whereas for the male, personal life stress ($p = .02$) and the D score were significant in the regression ($p < .001$) (Table 14, Model 4).

The stress of personal and family life was the only statistically significant predictor of male MCS, when the D score was not entered into the regression (Table 14, Model 2). With the D score, the stress of care-giving and the stress of behavior and communication were statistically significant ($p < .001$) (Table 14, Model 6). The stress of care-giving entered the regression negatively (Beta coefficient = -0.87) but the stress of the child's behavior and communication entered positively (Beta coefficient = 0.78). This was because they were highly correlated ($r = 0.74$). For MCS for males, the D score mediated the effect of stress of personal and family life (Beta coefficient -0.37 versus -0.63).

The stress of care-giving was the only statistically significant predictor of female MCS, when the D score was not entered into the regression ($p < .001$) (Table 15, Model 1). When both stress and the D score were entered, the D score was the only predictor of female MCS ($p < .001$) (Table 15, Model 3). This means that the D score is the mediator of personal and family life stress and the female MCS.

Modeling with Demographic Variables Included

Results for modeling with demographic variables included are presented in Table 16. Males were considered first. Age of the male parent was the only predictor for male physical health (accounting for 17% of the variance) as

measured by the PCS. Older males report poorer physical health, than younger males. The discrepancy in D score and the number of children living in the home full time or part time affected the males' mental health (accounting for 39% of the variance) as measured by the MCS.

Next, females were considered. Parent care giving stress was the only predictor for female physical health (accounting for 18% of the variance) as measured by the PCS. The discrepancy in 'how much there is' – 'how much there should be' in family functioning as measured by D score, was a predictor of female mental health (accounting for 31% of the variance) as measured by the MCS of the Rand 36 Health Inventory Version 1.0 HRQL measure.

Summary

This chapter presented the findings of a study to assess the relationship of parental stress, family functioning, and HRQL for parents of children with ASD within the conceptual frameworks adapted from Lazarus and Folkman's (1984) Transactional Model of Stress and Coping and Lakey and Cohen's (2000) Social Support Theory. Sequential procedures were run to quantify the relationship of the study variables. Four relationships were supported. In the first model (Figure 3) the predictor of parental care-giving stress accounted for 18% of the variance for female physical health. In the second, the only predictor for male physical health was age of the parent, accounting for 17% of the variance. In the third, the number of children living at home and discrepancy score for 'how much there is' - 'how much there should be' family functioning accounted for 39 % of the variance

in male mental health. In the fourth, the discrepancy score for 'how much there is' - 'how much there should be' family functioning accounted for 31 % of the variance in female mental health.

Table 14 Modeling for mediating effect of D scores for males

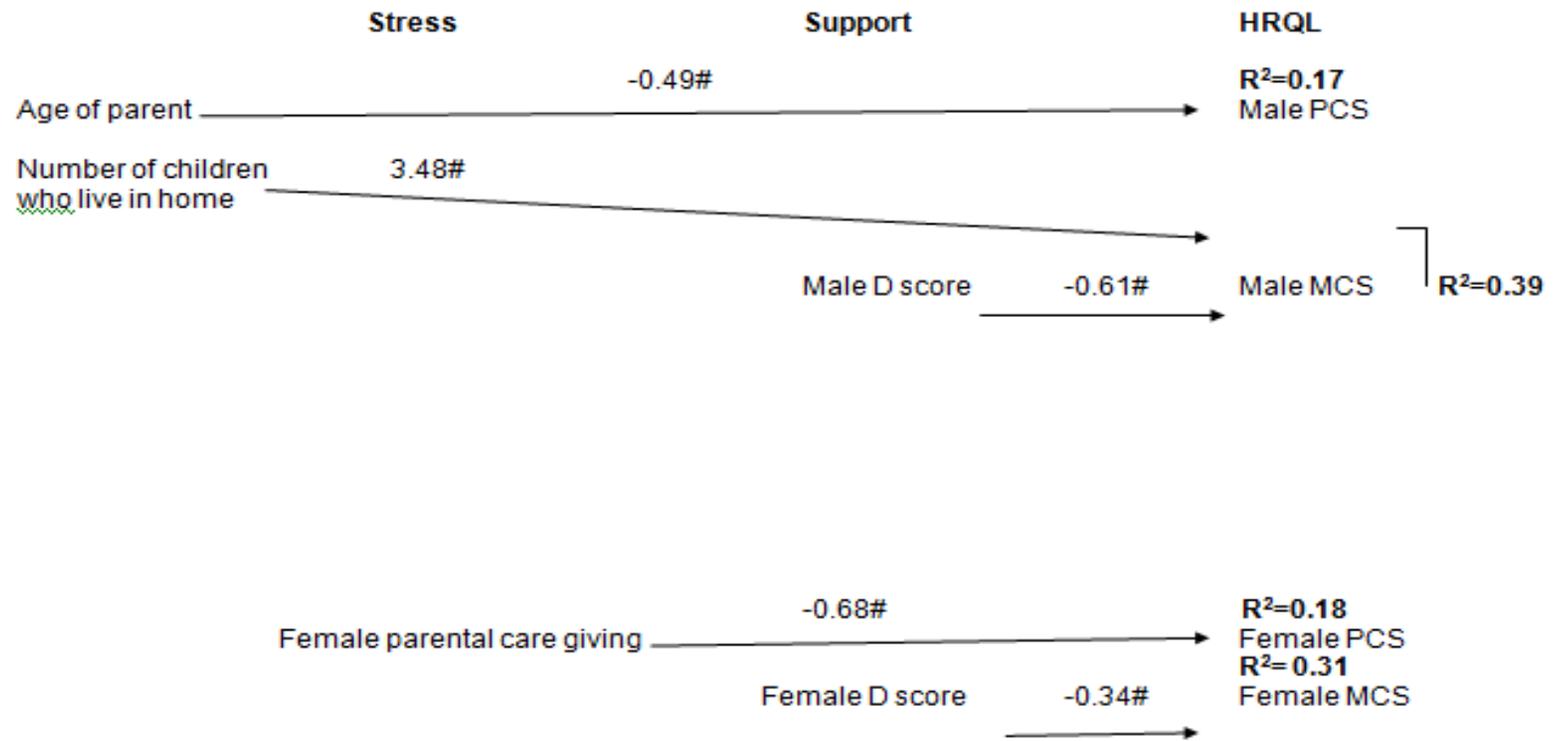
Variables	Model Statistics	Variables Statistics				
		B	SE B	Standardized B	t	p
Model 1: Stress predictors for male PCS Stress personal life subscale With D score, nothing changes	F(1,51)=4.99, p=.03, R ² =.09, adjusted R ² =.07	.26	.12	.30	2.23	.03
Model 2: Stress predictors for male MCS Stress personal life	F(1,51)=22.49 p<.001 R ² =.31, adjusted R ² =.29	-.63	.13	-.55	-4.74	.00
Model 3: Predictors for male MCS Total male D score	F(1,51)=26.03, p<.001 R ² =.34, adjusted R ² =.33	-.38	.08	-.58	-5.10	.00
Model 4: Predictors of male MCS Total male D score Stress personal life	F(2,52)=17.54, p<.001 R ² =.40, adjusted R ² =.38	-.27 -.37	.09 .15	-.39 -.32	-2.98 -2.42	.00 .02
Model 5: Predictors of male MCS Total male D score Stress of care-giving	F(2,50)=17.64, p<.001 R ² =.41, adjusted R ² =.39	-.32 -.49	.08 .19	-.48 -.29	-4.13 -2.54	.00 .01
Model 6: Predictors of male MCS Total male D score Stress of care-giving Stress of behavior and communication	F(3,49)=14.19, p<.001 R ² =.47, adjusted R ² =.43	-.39 -.87 .78	.08 .26 .36	-.59 -.52 .36	-4.80 -3.40 2.17	.00 .00 .04

Table 15 Modeling for mediating effect of D scores for females

Variables	Model Statistics	Variables Statistics				
		<i>B</i>	<i>SE B</i>	<i>Standardized B</i>	<i>t</i>	<i>p</i>
Model 1: Stress predictors for female PCS Stress of care-giving With D score, nothing changes	$F(1,49)=14.18, p<.001,$ $R^2=.22, \text{adjusted } R^2=.21$	-.75	.20	-.47	-3.77	.00
Model 2: Stress predictors for female MCS Stress personal life	$F(1,49)=13.01, p<.001$ $R^2=.21, \text{adjusted } R^2=.19$	-.54	.15	-.46	-3.61	.00
Model 3: Predictors for female MCS Total female D score	$F(1,49)=23.38, p<.001$ $R^2=.32, \text{adjusted } R^2=.31$	-.34	.07	-.57	-4.84	.00

Table 16 Predictors of HRQL

Variables	Model Statistics	Variables Statistics				
		<i>B</i>	<i>SE B</i>	<i>Standardized B</i>	<i>t</i>	<i>p</i>
Model 1: Predictors of male PCS	F(1,48)=11.05, p=.002					
Age	R ² =.19, adjusted R ² =.17	-.49	.15	-.43	-3.32	.002
Model 2: Predictors of male MCS	F(1,48)=27.34, p<.001					
Total male D score	R ² =.36, adjusted R ² =.35	-.43	.08	-.60	-5.23	.00
Model 3: Predictors of male MCS	F(2,47)=16.69, p<.001					
Total male D score	R ² =.42, adjusted R ² =.39	-.43	.08	-.61	-5.44	.00
Number of children live with fulltime		3.48	1.70	.23	2.05	.05
Model 4: Predictors of female PCS	F(1,45)=11.13 p=.002					
Stress parent care giving	R ² =.20, adjusted R ² =.18	-.68	.20	-.45	-3.34	.00
Model 5: Predictors of female MCS	F(1,49)= 23.38, p<.001					
Total female D score	R ² =.32, adjusted R ² =.31	-.34	.07	-.57	-4.84	.00



Beta
 D score= Absolute of discrepancy between how much there is and how much there should be
 PCS = Physical component of the Rand 36 item Health Inventory version 1.0
 MCS= Mental component of the Rand 36 item Health Inventory version 1.0

Figure 3. Model of relationships including demographic variables

Chapter Five: Discussion

In the current study, the relationships among parenting stress, family functioning and the HRQL for parents of children with ASD were addressed. A model adapted from the frameworks of Lazarus and Folkman's (1984) Transactional Model of Stress and Coping, and Lakey and Cohen's (2000) Social Support Theory was developed to test theoretical relationships. I will begin with a comparison of the descriptive findings of the present study and compare the findings to the extant literature. Next I will discuss the findings for each of the three research questions, the needs for further research and the clinical implications of the findings.

Interpretation of the Descriptive Findings

Findings for parenting stress totals on the PSS:A included a total scale mean of 71.18 (SD=25.7) for the males and females in the parenting dyads, which was similar to the total scale mean reported by Phetrasuwan (2003) of 75.01 (SD=22.65). The present study allowed for comparison of both partners in the parenting dyad. For all 4 sub-scale stress scores, women and men report high stress scores. This finding matches the results by Little (2002). Little posited that the high stress rating for women was related to fathers having more outlets for evaluating their self-worth in terms of their careers and ability to provide for their children. The Easter Seals (2009) study also reported that the primarily female samples were stressed by worry for the financial concerns for their ASD-

affected child. The stress perceptions for males and females, parenting the same ASD-affected child, are an important addition to the literature.

Both men and women in the present study found that dealing with the behaviors and communication with their children was the most stressful, while the basic care-giving was the least stressful. This finding matches other studies with male and female parent participants (Clark, 2007; Estes et al., 2009; Gray, 2003; Hastings, 2003; Herring et al., 2006; Hoffman et al., 2008), as well as other studies that had primarily mothers as participants (Clark, 2007; Estes et al., 2009). Addressing how to limit the challenging behaviors will be an important area for nursing intervention. Some child behaviors may not be amenable to interventions in that they are intractable features of severe ASD.

Other studies on mothers of children with autism found a found a relationship between parenting stress and the severity of autism (Hastings & Johnson, 2001; Tobing, 2005). The most recent literature posits that for children with ASD, it is possible that anxiety symptoms (rather than severity of ASD) that may be responsible for the behavioral difficulties (Reaven, 2009). Parents spend excessive amounts of time reassuring children but unfortunately there may not be much change in the anxiety or the behaviors (Chansky, 2004). Interventions targeted to decrease the child's anxiety should be considered when planning parental stress reduction interventions.

In the present study, the discrepancy in the expectations for family functioning (as measured by the FFFS) was found to mediate the parenting stress and the mental health component (MCS) of HRQL of parents. Males and

females differed in their expectations. The total mean discrepancy score for the FFFS (Table 7) was 33.06 (SD= 20.11) for men and 41.97 (SD=21.14) for women, indicating more discrepancy between 'how much there is now' and 'how much there should be' of a particular aspect of support in the 25-item questionnaire. The discrepancy scores for men match past studies' findings. Feetham et al. (2007) reported that discrepancy scores tend to range from 17-35. The discrepancy scores in this study were not only higher for the women, but were also higher than the range of scores in past studies reported by Feetham et al.

No past studies of parents of children with ASD have reported on this discrepancy using the FFFS. A few studies have collected data from both parents of children with a developmental disability (Allik et al., 2006; Deris, 2005; Kersh et al., 2006; Little, 2002). Assessment of the discrepancy between desired and current amounts of supports for parents of disabled children was first reported in the literature by Bristol, Gallagher and Schopler (1988). While they did not use the FFFS to assess the discrepancy between desires and perceptions of reality, they did use a tool that revealed disharmony between current and appropriate spousal support. The disharmony score was a significant predictor of perceived and observed parental adaptation (Bristol, Gallagher & Schopler, 1988).

In a sample of children with chronic disorders, Knafl and Deatrick (2003) found joint effort to manage illness with different views on how to manage the situation can affect family functioning. Although the parents work together they

may have different future expectations or a plan on how to get there which is a potential source of distress (Knafl & Deatrck, 2003).

Since the data collection for the present study, Brobst et al. (2009) reported similar important findings. The researchers compared 25 couples of children with ASD with 20 couples whose children had no developmental delay, assessing both behavior problems for the children and relationship satisfaction for the couples (Brobst et al., 2009). The children in the study ranged from 2-12 years. Parenting Stress was measured with the PSI-SF (Abidin, 1995). Relationship satisfaction was measured with the Relationship Assessment Scale (Hendrick, 1988), the Social Support Scale (Sarason, Sarason, Shearin, & Pierce, 1987), the Respect Toward Partner Scale (Hendrick & Hendrick, 2006) and the Commitment scale (Hendrick & Hendrick, 2002). This study found an important link between support from one's spouse and the relationship satisfaction. The researchers also found that when mothers of children were faced with more behavior problems in their children, they reported less support from their husbands. They recommend that parent support groups focus on emphasizing strengthening their relationships during times of stress, rather than just focusing on their roles as parents. They specifically recommend that parent couples need to be explicit in their appreciation and respect for each other. Although the researchers report limitations in the study, including a non diverse sample of Caucasian, educated individuals with above-average family incomes, the study adds to the limited amount of research addressing the influence of a child's behavior problems on couple's relationships.

Kersh et al. (2006) also found that for mothers and fathers of children with developmental disabilities (n=67 dyads), greater marital quality predicted lower parenting stress and fewer depressive symptoms above and beyond socioeconomic status, child characteristics and social support. For mothers and fathers, the child's overall level of functioning did not predict any measure of parental well-being. This is an important finding because relationship strength is a process that is conceivably changeable by nursing interventions.

In the present study HRQL was measured by the Rand 36-Item Health Survey 1.0, which allowed for reporting on the 8 subscales as well as on 2 components (MCS and PCS). The average sub-scale scores (Table 8) range from a low of 33.28 for the energy and fatigue subscale for women and a high of 88.59 for men. All of the male subscale averages appeared to be higher than the corresponding female subscale average. This finding reflects the perception of better health in each of the 8 areas addressed by the questionnaire. Similar results were found for the MCS and PCS reports for males and females. Males appear to have higher scores for physical health and mental health. However, the physical health scores for both men and women are close to the reported average of 50.

In the present study, the sample appears to self report average physical health. Conversely, the MCS scores appear to be much lower than the expected norm of 50 (Ware et al., 1994), with females appearing to have lower scores than males. Past studies, with mostly female participants have also found

psychological distress in parents of children with ASD (Allik, 2006; Phetrasuwan, 2003).

Discussion of Findings for Hypotheses and Research Questions

Hypothesis A. Hypothesis A was substantiated. Higher discrepancy scores for FFFS were related to lower HRQL for both males and females, for the mental health component of the HRQL. Higher discrepancy for males was correlated with higher physical health component of the HRQL. The opposite was true for females. Using Pearson's r , females' D scores also were negatively correlated with their PCS. This finding matches previous studies (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001b; Hastings et al., 2005) that found a discrepancy in expectations negatively affects both mental and physical health for females. This may be related to the predominantly emotion-focused coping style of females, rather than gender alone.

Hypothesis B. Hypothesis B was not substantiated. A total similarity score was to be computed for each parent dyad. However, the sample of 64 dyads was not large enough to do the analysis. However, it was determined by the statistician that a Wilcoxon Signed Ranks Test should be performed to detect differences between the 2 related groups (males and females). The test detected a statistically significant difference between males' and females' discrepancy scores. Females had wider discrepancy scores than males. In addition, the planned structural equation model analysis was not possible given the sample recruited.

Question 1. What is the influence of one spouse's perceived family functioning as measured by the FFFS on the other spouse's perceived family functioning?

Females had a wider discrepancy scores than males (statistically significant). In addition, male D score and female D scores were positively related. When males had a wide discrepancy between expectations and reality, so too did females. This matches findings by Knafl and Deatrick (2003) who studied children with chronic conditions, not just ASD. They found that although parents have reported joint efforts to manage illnesses, they are known to have different views on how they define and manage the situation. Males tend value financial contributions and females value emotional support (Deris, 2005). The difference in values could account for the difference in the discrepancy score.

Question 2. What is the relationship of parenting stress, family functioning and parental HRQL as measured by the Parenting Stress: Autism scale, FFFS and the Rand 36-Item Health Survey 1.0 for parents of children with ASD? A

Pearson's r correlation was run on all subscales of the PSS:A, the total female D score, total male D score, male PCS, female PCS, male MCS, and female MCS. The stress variables were all positively related to each other and the D score. The total female D score was related to all variables except for male PCS. As the discrepancy in 'how much there is' and 'how much there should be' for the FFFS rises, so too does parenting stress. Tobing and Glenwick (2006) posited that it is whether or not a parent's expectation has been met that determines the usefulness of a support.

The D score for males was related to all variables except the stress of advocating for the child's needs and the PCS male. This could be explained by literature that reports a majority of females take on a disproportionate burden of caring for the ASD-affected child (Bristol, Gallagher, & Shopler, 1988; Winter, 2005).

The MCS was generally negatively related to the stress variables and D scores. As stress and the D score increased, the MCS and PCS of HRQL decreased. The D score mediated the effect of fathers' stress in their personal lives on their mental health related quality of life.

Some of these findings could occur by chance, just by virtue of the number of correlations run. The regression analysis and the resultant models (Table 16), best explain the relationships of stress, family functioning and HRQL.

Question 3. Does family functioning mediate the relationship between parental stress and parental HRQL? While the D scores were not predictive of PCS, they were predictive of females MCS, accounting for 31 % of the variance. The D scores are higher for females than males, indicating that they had a different amount of support than they perceived they needed. Females also had lower PCS and MCS scores than males, and higher stress scores on all the stress subscales than the males. The amount of variance that the D score accounts for is large. Nursing interventions addressing the discrepancy in expectations could contribute to improved mental health for parents of ASD-affected children.

Additional analysis of demographic variables found that the age of the father was the only predictor of male PCS. However, the stress of care-giving was predictive

of female PCS, accounting for 21% of the variance (Table 15, Model 1). The physical work of care-giving impacts women most likely because they are often the main care giver (Little, 2002). The work of caring for a child with ASD is physically draining. It includes managing sleep problems and assisting with bathing and dressing.

Significance of Findings

The findings in the present study match past research in which support is conceptualized not as a commodity but rather as a result of a social process. Past research on parents of children with ASD report mothers with psychological distress had low perceived social support in the form of supportive relationships (Bromley et al., 2004; Tobing & Glenwick, 2006) and had children with problem behaviors (Allik et al., 2006). Findings in the present study support the two theories that framed the study. In the Transactional Model, ambiguity and social networks are causal antecedents of stress. There is ambiguity related to the diagnosis treatment options (AHRQ, 2009) and prognosis for children with ASD (Little, 2002). Social networks are thought to mediate stress. Networks also have a positive impact on parental health according to this model. In the social support model (Reis & Collins, 2000) the processes operating within relationships, rather than the existence of the relationship account for feelings of support. In this study discrepancy scores in how much there is and how much there should be for the items in the FFFS were related to the HRQL of parents of children with ASD. Next steps in this program of research will be presented.

Further Research

One area of future research involves the FFFS. A further analysis of the importance scores on the FFFS merits investigation. In the present study, importance scores (C scores) were calculated (Table 7). The mean C scores for women appeared to be higher than for men. T-tests could be run to assess if there are statistically significant differences. Further data analysis to look at how spouses differ on perceived importance scores for the FFFS, would highlight priority areas for nursing interventions. Parent comments on the FFFS about what they found to be helpful and not helpful, merits analysis to discern themes. The themes could be reported in a short article and incorporated into nursing interventions as well. Another analysis would take into account the entire sample of 387 parents, looking for the differences in the discrepancy scores when only one parent filled out the questionnaires.

A second area of research would involve further statistician consultation about the possibility of dyadic analysis. Data was gathered on mothers and fathers in the present study. A couple score could be entered into a regression. Description of potential outliers and distributional differences would provide guidance for subsequent development and testing of interventions. A comparison could be made to the results gathered in this study that looks at the gender data individually. The analysis would yield important results about the differences in dyadic and aggregate analysis.

A third area of research involves measuring parent and child outcomes after parental participation in a parenting program. The parenting program would

be designed based on the findings of the present study along with literature review. The Rand 36 Health Inventory Version 1.0 is a measure of HRQL that has been extensively used in longitudinal studies so HRQL could be an outcome variable in such research.

The current state of the science is that the outcome measures generally include depression. An important contribution to the state of the science would be to measure different outcomes. For example, the review of literature in the present study revealed that the behaviors of the child, including anxiety are the most distressing for parents. A study that measures a child's anxiety level and parent stress would contribute to the state of the science.

Another potential study is one that explores the positive impact having a child with ASD has had on the parents and family. There is debate on the Autism Speaks web site about the benefits of high functioning ASD. This would add to the state of the science in terms of successful outcomes for parents and their child.

Implications of the Research for Nursing Practice, Education and Research

The findings of the study guide nurses regarding which specific areas to target to reduce parental stress and distress and help promote well-being for parents of children with ASD. Nurses care for parents of children with ASD in many different settings including pediatric primary and specialty care clinics, child developmental centers, inpatient units, over the telephone, in schools and in parishes (Phetrasuwan & Miles, 2009). In all of these settings, children and

families benefit from family centered care. Based on the results of the present study there are several interventions that nurses could implement that may affect parenting stress, family functioning and parental mental health and physical health.

The first intervention is based on the finding that females have wider discrepancy than males in their expectations for family functioning. Lazarus and Folkman (1988) discuss that processes are changeable through interventions. Nurses may have the opportunity to make a difference in the lives of parents of children with ASD by an intervention of asking open ended questions that give parents the opportunity to reflect on their own expectations for family functioning. The thoughts and emotions for parents are processes that are changeable through such an intervention. In the present study, as well as in past literature (Bristol et al., 1988; Deris, 2005) there are often gender-based discrepancies between expectations for support and the amounts and types of support one perceives are available.

Understanding the areas that are important to a parent is a first step in matching the appropriate supports for parents' individual expectations. Facilitation of this important conversation for parents by a professional may be necessary as parents may become withdrawn, frustrated or angry when they feel there is no hope (Ariel & Naseef, 2009). Bristol, Gallagher, and Schopler (1988) concluded that the mothers of developmentally disabled children carry a disproportionately heavy burden. How well mothers of disabled children function in terms of depression, marital adjustment, and parenting appears to be related

to their partner's capacity to be supportive. How well fathers function, particularly as parents is related to perceived support from their wives. Discussing issues in a way that helps both parents feel understood and find solutions to problems is most effective for a co-parenting strategy (Ariel & Naseef, 2009).

Parents of children with ASD should be assessed for not only for their expectations for family functioning, but also for their stressors, including the child's behavior. A second suggested intervention relates to the finding parents are most stressed by the child's behavioral problems. Although the stress of behavior and communication subscale was not a statistically significant predictor of male or female mental health in the present study, the stress subscale of personal and family life which includes the item 'helping family members cope with the child's behavior' was a predictor of male mental health. Assisting parents with behavioral interventions for managing their children is important. Of the four subscales for parenting stress, the behavior and communication subscale had the highest mean score. Problem behaviors are the result of underlying communication, social and sensory issues of ASD. Augmentive communication devices can improve the child's communication, and may subsequently decrease problem behaviors and the parents' stress response to the problem behaviors. Addressing the underlying anxiety that prompts challenging behaviors is another important intervention. Anxiety control is difficult to achieve and requires both environmental and often pharmacological management. Parents need to learn the behavior and environmental modifications that they must do in order to provide a calm, structured, predictable atmosphere for the ASD-affected child.

Parents must also choose physicians to manage medications to control anxiety. To this end, care of the child could involve making choices and keeping appointments with all of or at least some of the following providers: pediatricians, psychiatrists, psychologists, other specialty physicians such as neurologists or gastroenterologists, speech therapists, music therapists, occupational therapists, and teachers. Each of these providers offers advice and choices about treatment options. Since many of the therapies are not evidence based (AHRQ, 2009), the parents are vulnerable to the providers, to offer them choices at a level they can understand. As a population, children with ASD are vulnerable by the nature of their age, condition and the lack of communication ability. They rely on their parents to make good choices for them. Nurses can play an important role as a bridge for parents to access the resources they need to advocate for their child. The stress of care giving was a predictor of the physical health of female parents of children with ASD, accounting for 20 % of the variance. Nurses can assist parents with the basic care giving stressors that present with ASD. These include: sleep disturbances, temperament, toileting, and communication and learning disabilities. Advocating that a child be evaluated by the appropriate health care professional to develop a strategy to manage these basic stressors is crucial.

Parents benefit from simplified processes for accessing support. They tend to seek out other parents of children with ASD to find support. Parents need services (Ariel & Naseef, 2009) as well as other parents to talk to (Deris, 2005). The Autism Society of America web site www.autism-society.org lists local

chapters. Local Autism Societies offer a variety of support and education including parenting programs, as well as information about community resources. Support groups that focus on strengthening parental relationships during times of stress, rather than just focusing on their roles as parents, are recommended. Brobst et al. (2009) specifically recommend that parent couples need to be explicit in their appreciation and respect for each other. Nurses can assess for and encourage parents to verbalize their appreciation and respect of each other. Trusting relationships are recognized by parents as being most supportive (Ariel & Naseef, 2009). Trusting relationships foster optimism rather than despair. Optimism fosters psychological well being (Baker et al., 2005).

Parenting series that present knowledgeable speakers at autism societies are good places for parents to not only learn but also to meet other parents of children with ASD. When referring parents to parenting programs literature shows that men tend to prefer programs that have a recreational element rather than a classroom like approach (Winter, 2005). Programs that help parents learn how to decrease problem behaviors by mindfulness training are promising and recommended (Singh et al., 2007).

Nurses can also be supportive to parents by not contributing to the stress the parent already feels. Parents are very sensitive to the attitudes that professionals display toward them. This may be because of the past attitudes of health care providers, who were known to blame parents for the misbehavior of children with autism (Hyvonen, 2004). Children with ASD present with behavioral challenges. Nurses, like anybody else, may be tempted to make judgments about

parenting skills. Parents feel societal pressure to have children under control. Mothers may even isolate themselves as their children grow older and they lose hope for their future (Little, 2002). They will not feel supported by nurses who put them under what amounts to more pressure. When nurses display a knowledgeable approach by speaking slowly, waiting for responses and not being flustered by repetitive behaviors that children with ASD often present with, the door is opened to a relationship of trust.

Strengths, Weaknesses, and Limitations

While a total of 367 parents of children with ASD, representing 46 of the 50 states, filled out all four questionnaires for the study, the majority these were the mothers of the children, not the fathers. The sampling difficulties were anticipated as fathers of children with ASD are historically underrepresented in literature on parenting stress (Anderson, 2009; Clark, 2007; Easter Seals, 2009; Estes et al., 2009; IAN, 2009; Phetrasuwan, 2003). Although most of the states were represented, the parents in both the larger sample (n=387) and the smaller sample (n=64 dyads) was not representative of the larger population of parents of children with ASD. While the cause of ASD is not known, it is known to be a disorder that has no known demographic tendencies for expression. From the 387 parents, there were 64 parenting dyads identified. The sample of 64 dyads was not large enough to perform structural equation modeling.

The diagnosis of ASD was based on parent report. This is a limitation. While the recruitment for participants in the study took place in clinics,

conferences, classes and on-line in ASD- focused list-serves and websites, it is possible that a parent of a child without ASD might have participated in the study. The diagnosis was not confirmed as there were already four lengthy surveys in the study and the extra survey was seen as a potential burden to participants. The sample in this study was biased in that the majority of the participants were white, college educated and married. The absence of diversity is a limitation. The HRRB recruitment flyer for the study was made available in both electronic and paper format in clinics, and at conferences and classes with diverse participants. Completing the FFFS may have been difficult for people who do not have a high school education (Grotevan & Carlson, 1989).

The use of self-report data is a limitation. The Parenting Stress Scale: Autism (Miles & Phetrasuwan, 2003) is a new tool for which face validity, construct validity and internal consistency estimates were provided in one study (Phetrasuwan, 2003). The time involved to complete the questionnaires was long (at approximately 20 minutes when completed by the researcher). Although clear expectations for the 20-40 minutes time commitment was explained in the participant recruitment flyer, it may have been the reason some participants did not complete all the surveys. Although the importance of the need for the dyad data was explained to the parents in the flyer, there were more females than males in the total sample.

There are threats to internal and external validity identified in the study design. By its nature as a cross-sectional study, information was collected from participants only once. The timing of the data collection might not be

representative of the participants' reality the majority of the time. For example, the participant could have had a particularly bad day when they completed the surveys. The study only included those with Internet access. Parents without Internet access were excluded from the study. This poses a threat to internal validity.

It was possible for participants to fill the survey out more than once. Even though Survey Monkey web site technology has a feature that could limit only one person per IP address from filling out a survey, this feature was not used in this study. Since we wanted dyads to fill out questionnaires separately, the feature could not be used. Participants could conceivably have filled out surveys more than once. Computer hardware or software or web site technology problems could have interrupted the completion of a set of forms as well.

The parent dyads where both spouses participated may also be biased. Therefore, the remaining women in the larger sample, whose spouses/partners did not participate, are of interest to the researcher. While their data is not the subject of this study, it merits investigation in a future study for difference in the study variables between women who had spouses that filled out questionnaires and those that did not.

Summary

The purpose of this study was to gain a better understanding of the relationships of parenting stress, family functioning, and HRQL for parents of children with ASD. ASD-affected children and their parents are members of a

vulnerable population stemming from a chronic condition with no known cure. Being providers of family centered care, nurses are charged with the responsibility with advocating for both the mental and physical health of parents of ASD-affected children. Based on the frameworks of Stress and Coping theory and Social Support Theory, a model was developed to test the hypothesized relationships between stress, family functioning, and HRQL.

The findings of the study indicate that the discrepancy score of the FFFS mediates parenting stress' relationship with the MCS of the HRQL for both male and female parents of children with ASD. Interventions that target the child's behavior and communication could benefit parents. Future research could focus on the evaluation of interventions designed to improve parents' mental health as measured by the MCS of the Rand 36 Health Inventory Version 1.0. The physical health of female parents could benefit from having support with the care-giving. Parenting programs for both parents that encourage parents to reflect on and demonstrate their appreciation of the other and their expectation for family functioning as well as for planning for the future are indicated. Arriving at strategies that help the parents of the ASD-affected child enjoy improved mental and physical health offers some control over important aspects of a life that will always be a challenge.

Appendix A: Study Enrollment Form

Thank you for agreeing to participate in our study. We need some preliminary information about you.

Your gender: male female

Month of your child's birthday _____

Month of your birthday _____

Month of your spouse's birthday _____

Initial of your first name _____

Initial of your spouse's first name _____

State you live in _____

Your age: _____

Your child with ASD's age: _____ gender male female

Your child with ASD's age: _____ gender male female

Your child with ASD's age: _____ gender male female

Your relationship to the child(ren): mother father other _____

Length of relationship with your significant other _____

Your marital status:

married

single

separated

divorced

widowed

other, please describe _____

Your race/ ethnicity: (check all that apply)

Asian

black

Hispanic

white

other, please

Do you live alone? no yes

If no, how many adults live with you? _____ ages _____ full-time _____ part-time _____

How many children live with you? _____ ages _____ full time _____ part time _____

Your Occupation (Job): _____ If retired, list job before you retired _____

Your spouse or partner's Occupation (Job): _____ If retired, list job before he or she retired _____

Highest level of education

Less than 7th grade

Junior high school (9th grade)

Partial high school (10th or 11th grade)

High school graduate

Partial college (at least 1 year)

College or university graduate

Graduate degree

You

Your spouse/partner's

At what age did you suspect your child had Autism Spectrum Disorder? _____

At what age was your child diagnosed with Autism Spectrum Disorder? _____

What is your child's diagnosis? Autism _____ Pervasive Development Delay (PDD-NOS) _____ Aspergers _____

Does your child have any other medical problems? (if so list here) _____

Appendix B: Study Recruitment Flyer

Are you the parent of a child aged 2-18 years old with Autism Spectrum Disorder (ASD)?

Would you like to participate in a study?

What is the study?

The study looks at how parenting stress and relationships with a spouse affect the health of parents of children with ASD?

What will I have to do?

If you participate in the study, you will be asked to complete 4 questionnaires on a secure website. This will take approximately 20-40 minutes. We would like both parents to fill out a set of questionnaires.

Will I receive anything for participating?

No

Are there risks or benefits?

The study requires your time. Answering the questions may be stressful. The benefits may be that the understanding may lead to better support for parents of children with ASD.

Where can I find the results of the study?

The study results will be summarized in an upcoming newsletter in the Autism Society of South Eastern Wisconsin Newsletter posted on their website:

www.asew.org **If you would like to participate or want more information**

please contact Norah Johnson RN MSN CPNP PhD candidate at

njohnson@chw.org or 414-337-7718

OR You can visit the study website at: <http://www.mommyruns.com>

Appendix C: Parenting Stress Scale: Autism

We are interested in knowing about your experiences as the parent of a child with autism or autism spectrum disorder. Listed below are items that reflect aspects of parenting that some parents have found difficult or stressful. We are interested in your experiences. After each statement, circle the appropriate number that indicates how stressful the experience or responsibility has been for you in the past month. By stressful, we mean the experiences or responsibilities described below caused you to feel anxious, upset, or tense. If an item does not apply to your experience, circle N/A—not applicable.

BEHAVIOR AND COMMUNICATION

Managing my child's behavior when in public places	N/A = Not applicable 1 = Not stressful 2 = Somewhat stressful 3 = Moderately stressful 4 = Very stressful 5 = Extremely stressful
Helping my child learn how to be with other children	N/A = Not applicable 1 = Not stressful 2 = Somewhat stressful 3 = Moderately stressful 4 = Very stressful 5 = Extremely stressful
Learning how to best communicate with my child	N/A = Not applicable 1 = Not stressful 2 = Somewhat stressful 3 = Moderately stressful 4 = Very stressful 5 = Extremely stressful

<p>Helping my child communicate with others adequately</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Trying to figure out what my child needs or wants if he/she is having a tantrum</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Managing my child's demanding behaviors, mood changes and upset feelings</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>

ADVOCATING FOR MY CHILD'S NEEDS

<p>Communicating clearly to the school or day care or babysitters about my child's special needs</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Communicating with health care professionals about my child's behavior and his/her needs</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Making sure my child is getting the appropriate help in school</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Helping family members understand my child's condition and related needs</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>

PARENTAL CAREGIVING

<p>Feeling like my child doesn't want to be cuddled, touched, or held as much as I'd like</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Dealing with my child's problems related to eating</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Managing my child's problems with sleep</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Handling my child's problems related to bathing and dressing</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>

<p>Knowing how to appropriately discipline my child</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Overcoming my feelings of protectiveness towards my child</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Trying to keep my child's life as normal as possible</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Keeping my child on a regular routine at home</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>

PERSONAL AND FAMILY LIFE

<p>Helping other family members cope with my child's behavior</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Dealing with differences of opinion about care of my child with my husband and/or grandparents</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Balancing the needs of my child with those of other family members</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Trying to keep family life as normal as possible despite my child's condition</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>

<p>Trying to understand how much to involve my child's siblings or other family members in the care of my child</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Having financial problems related to my child's problems</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Finding time for my own activities and needs</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Difficulty giving myself permission to take time for my own activities and needs</p>	<p>N/A = Not applicable</p> <p>1 = Not stressful</p> <p>2 = Somewhat stressful</p> <p>3 = Moderately stressful</p> <p>4 = Very stressful</p> <p>5 = Extremely stressful</p>
<p>Feeling that my child's problems</p>	<p>N/A = Not applicable</p>

control my life	1 = Not stressful 2 = Somewhat stressful 3 = Moderately stressful 4 = Very stressful 5 = Extremely stressful
Meeting the demands of my other work responsibilities and care of my child	N/A = Not applicable 1 = Not stressful 2 = Somewhat stressful 3 = Moderately stressful 4 = Very stressful 5 = Extremely stressful

Cronbach's alpha for total scale = .94

Note. Scoring Range: 1-5

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Appendix D: Feetham Family Functioning Survey

In this survey you are asked to rate activities (functions) that occur in your family and with family members. For each family function you are asked to answer three questions:

How much is there now?
 How much should there be?
 How important is this to you?

Please answer all three questions for each family function by circling the number which represents how you feel now about the family function. The term spouse refers to your husband or wife or the person who assumes the function of a spouse/partner. If you do not have a person who assumes the functions of a spouse/partner role, answer the questions based on how much you want the functions met. Please try to answer all items.

Please mark your answer by circling the number

Much							Little
1. The amount of discussion with your friends regarding your concerns and problems. a. How much is there now? b. How much should there be? c. How important is this to you?	1	2	3	4	5	6	7
2. The amount of discussion with your relatives regarding your concerns and problems (do not include your spouse/partner). a. How much is there now? b. How much should there be? c. How important is this to you?	1	2	3	4	5	6	7
3. The amount of time you spend with your spouse/partner . a. How much is there now? b. How much should there be? c. How important is this to you?	1	2	3	4	5	6	7
4. The amount of discussion of your concerns and problems with your spouse/partner . a. How much is there now? b. How much should there be? c. How important is this to you?	1	2	3	4	5	6	7
5. The amount of time you spend with your neighbors . a. How much is there now? b. How much should there be? c. How important is this to you?	1	2	3	4	5	6	7
6. The amount of time you spend in leisure/recreational activity. a. How much is there now? b. How much should there be? c. How important is this to you?	1	2	3	4	5	6	7
7. The amount of help from your spouse/partner with family tasks such as care of children, house repairs, household chores, etc. a. How much is there now? b. How much should there be? c. How important is this to you?	1	2	3	4	5	6	7

8. The amount of help from relatives with family tasks such as care of children, house repairs, household chores, etc. a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
9. The amount of time with health professionals (doctors, nurses, social workers, etc.). a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
10. The amount of help from your friends with family tasks such as care of children, house repairs, household chores, etc. a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
11. The number of problems with your child(ren) . a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
12. The amount of time you spend with your child(ren) . a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
Do you have child(ren) in school?	Child in School Yes No
13. The amount of time your child(ren) miss school. a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
14. The number of disagreements with your spouse/partner . a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
15. The amount of time you are ill. a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
16. The amount of time you spend doing housework (cooking, cleaning, washing, yard work etc.). a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
17. The amount of time you miss work (including housework). a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
18. The amount of time your spouse/partner misses work (including housework). a. How much is there now? b. How much should there be? c. How important is this to you?	1 2 3 4 5 6 7 1 2 3 4 5 6 7 1 2 3 4 5 6 7
19. The amount of emotional support from friends . a. How much is there now? b. How much should there be?	1 2 3 4 5 6 7 1 2 3 4 5 6 7

c. How important is this to you?	1	2	3	4	5	6	7
	1	2	3	4	5	6	7
20. The amount of emotional support from relatives .							
a. How much is there now?	1	2	3	4	5	6	7
b. How much should there be?	1	2	3	4	5	6	7
c. How important is this to you?	1	2	3	4	5	6	7
21. The amount of emotional support you're your spouse/partner							
a. How much is there now?	1	2	3	4	5	6	7
b. How much should there be?	1	2	3	4	5	6	7
c. How important is this to you?	1	2	3	4	5	6	7
22. The amount of time your work routine is disrupted (including housework).							
a. How much is there now?	1	2	3	4	5	6	7
b. How much should there be?	1	2	3	4	5	6	7
c. How important is this to you?	1	2	3	4	5	6	7
23. The amount of time your spouse's/partner's work routine is disrupted (including housework).							
a. How much is there now?	1	2	3	4	5	6	7
b. How much should there be?	1	2	3	4	5	6	7
c. How important is this to you?	1	2	3	4	5	6	7
24. The amount of satisfaction with your marriage (relationship with spouse/partner).							
a. How much is there now?	1	2	3	4	5	6	7
b. How much should there be?	1	2	3	4	5	6	7
c. How important is this to you?	1	2	3	4	5	6	7
25. The amount of satisfaction with sexual relations with your spouse/partner .							
a. How much is there now?	1	2	3	4	5	6	7
b. How much should there be?	1	2	3	4	5	6	7
c. How important is this to you?	1	2	3	4	5	6	7

26. What is most helpful to you now?

27. What is least helpful to you now?

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Appendix E: RAND 36-Item Health Survey 1.0 Questionnaire I

[Unformatted version](#)

1. In general, would you say your health is:	
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. Compared to one year ago , how would you rate your health in general now ?	
Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

(Circle One Number on Each Line)

	Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at All
3. Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	[1]	[2]	[3]
4. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	[1]	[2]	[3]
5. Lifting or carrying groceries	[1]	[2]	[3]
6. Climbing several flights of stairs	[1]	[2]	[3]
7. Climbing one flight of stairs	[1]	[2]	[3]
8. Bending, kneeling, or stooping	[1]	[2]	[3]
9. Walking more than a mile	[1]	[2]	[3]

10. Walking several blocks	[1]	[2]	[3]
11. Walking one block	[1]	[2]	[3]
12. Bathing or dressing yourself	[1]	[2]	[3]

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health?**

(Circle One Number on Each Line)

	Yes	No
13. Cut down the amount of time you spent on work or other activities	1	2
14. Accomplished less than you would like	1	2
15. Were limited in the kind of work or other activities	1	2
16. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

(Circle One Number on Each Line)

	Yes	No
17. Cut down the amount of time you spent on work or other activities	1	2
18. Accomplished less than you would like	1	2
19. Didn't do work or other activities as carefully as usual	1	2

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(Circle One Number)

Not at all 1

Slightly 2

Moderately 3

Quite a bit 4

Extremely 5

21. How much **bodily** pain have you had during the **past 4 weeks?**

(Circle One Number)

None 1

Very mild 2

Mild 3

Moderate 4

Severe 5

Very severe 6

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

(Circle One Number)

Not at all 1

A little bit 2

Moderately 3

Quite a bit 4

Extremely 5

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks** . . .

(Circle One Number on Each Line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt downhearted and blue?	1	2	3	4	5	6
29. Did you feel worn out?	1	2	3	4	5	6
30. Have you been a happy person?	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6

32. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle One Number)

All of the time 1

Most of the time 2

Some of the time 3

A little of the time 4

None of the time 5

How TRUE or FALSE is each of the following statements for you.

(Circle One Number on Each Line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
33. I seem to get sick a little easier than other people	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I expect my health to get worse	1	2	3	4	5
36. My health is excellent	1	2	3	4	5

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