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Respite Care and Marital Quality: Families with a Child

Diagnosed with an Autism Spectrum Disorder

Amber Harper

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of

Master of Science

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Abstract

Parents of children with an autism spectrum disorder (ASD) are at greater risk than other couples for having higher stress levels and lower marital quality. Respite care has been suggested as a way to help alleviate stress. This study investigated the relationship between respite care and marital quality; and the potential of mother stress and father stress as mediating variables. One hundred and one couples, each consisting of a mother and a father who lived with their child with an ASD, were given questionnaires including a respite questionnaire, *Revised Dyadic Adjustment Scale*, *Experience in Close Relationships Questionnaire*, and *Daily Hassles and Uplifts Scale*. Results showed that the amount of respite care was positively related to marital quality for both husbands and wives. Husband and wife stress and husband and wife uplifts mediated the relationship between respite care and marital quality for both husbands and wives, indicating these variables of stress and uplifts were processes through which respite care had an indirect effect on marital quality. Results suggest that policy makers should develop strategies for providing respite care for families with children diagnosed with an ASD.

Keywords: Respite Care, Marital Quality, Autism Spectrum Disorder

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DESCRIPTION OF THESIS STRUCTURE

This thesis, *Respite Care and Marital Quality: Families with a Child Diagnosed with an Autism Spectrum Disorder*, is written in a hybrid format. The hybrid format combines traditional thesis requirements and journal publication formats.

The thesis conforms to length and style requirements for submitting for a journal article publication. This thesis includes two reference lists. The first reference list contains references included in the journal-ready article, and the second reference list contains references included in the literature review. Appendices A-C include the literature review, measures, and consent to be a research subject, respectively.

Respite Care and Marital Quality: Families with a Child

Diagnosed with an Autism Spectrum Disorder

Background

Pervasive Developmental Disorders (PDDs) usually include deficits in basic skills such as communication, social skills, and imaginative skills. Currently, there are five recognized subcategories of PDDs, which include Autism, Asperger Syndrome, Childhood Disintegrative Disorder (CDD), Rett Syndrome, and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). Due to the similarities and differences of each subcategory, they are often referred to as Autism Spectrum Disorders (ASD); yet, some professionals have suggested that only Autism, Asperger Syndrome, and PDD-NOS qualify as Autism Spectrum Disorders (Rice, 2006).

Autism is a complex disorder that affects a child prior to the age of three in three areas of development: social interaction, communication, and behavior (American Psychiatric Association, 2000). The criterion for being diagnosed with Autism requires that a child exhibit six or more symptoms from these three areas of delay. The child must have at least two symptoms from the social interaction category, one from the communication category, one from the behavior category, and the remainder can come from any of the categories (American Psychiatric Association, 2000). Asperger Syndrome is similar to Autism due to complications in social interaction and behavioral repertoire, but people with Asperger Syndrome have an average to above average intelligence and no significant communication impairments. CDD has similar deficits, but the child develops appropriately up until the ages of 2 to 10 years of age. Between 2

and 10, the child starts to lose skills they have developed, such as language, and they may even lose bowel control. Rett Syndrome has similar characteristics to Autism except, there are problems in physical development, motor development, and coordination. PDD-NOS is a category reserved for those who have characteristics along the spectrum of Autism, but not significant enough for a diagnosis of any of the other four Pervasive Developmental Disorders.

According to the Centers for Disease Control and Prevention (CDC) (Rice, 2006), one child in every 110 children in the United States in 2006 was classified as having an ASD. Furthermore, the CDC estimated that one male child in every 70 and one female child in every 315 is affected with an ASD (Rice, 2006). These numbers have changed drastically since the 1980's, when it was reported that one in every 2,000 children had Autism. This increase may be due to the fact that criteria for diagnosing an ASD have changed since the 1980's. In the 1980's, the term Autism referred to an autistic disorder, but the change in diagnostic criteria introduced Autism Spectrum Disorders (ASD), and there are multiple diagnostic categories that fall under this umbrella of an ASD. Since children are being diagnosed with an ASD more frequently, this most likely means that more families will need to learn how to parent a child with an ASD.

Parenting, in general, can be stressful and taxing, but parenting a child with an ASD is even more stressful and burdensome. Brobst, Clopton, and Hendrick (2009) compared parents raising children without a developmental disability to parents raising a child with an ASD. The parents of children with an ASD experienced greater stress and lower relationship satisfaction, even though the two groups of couples did not differ in their support for one another, in their respect for each other, and in their commitment to one another. However, Burr and Klein (1994) posited that viewing stress alone represented only one facet of an individual's experience and

that considering stress without also considering personal resources and coping strategies may represent a distorted picture. The ABCX crisis theory (McCubbin & Patterson, 1983) suggests that stress and coping resources, along with personal perception of how the stress and resources interact, presents a fuller representation of actual experience. One of the strengths of this study is that stress, as well as resources in the form of daily uplifts, was taken into account. Daily uplifts were described as those events or persons that one perceives as uplifting (Lazarus & Folkman, 1984).

Lee, Harrington, Louie, and Newschaffer (2008) investigated the quality of life of families with children with an ASD, Attention Deficit Hyperactive Disorder (ADHD), and compared them with families that reported no concerns about their children. Parents with a child with an ASD reported that the burden of caregiving was significantly higher in comparison to the two other groups. Parents of children with an ASD reported higher levels of child care burden, attended religious services less, and were more likely to quit their jobs due to child care problems. Their children missed more school, repeated grade levels more often, and participated less in activities and events. Families of children with an ASD participated less in community services (Lee, et al., 2008).

Families with a child diagnosed with an ASD report difficulties in family and marital issues (Higgins, Bailey, & Pearce, 2005). These families have significantly lower family cohesion and family adaptability than do families with children who have no diagnosis. Couples in the families with a child with an ASD reported lower marital happiness. It may be important to consider how to help couples strengthen their relationship in facing the stresses and strains of raising a child with an ASD. One possible resource to help these parents might be respite care.

Respite Care as a Resource

Respite care is giving a limited break to caregivers of people who are difficult to care for. Respite care may be given inside the home and the caregivers leave, or it may be provided outside of the home where the person being cared for is taken out to do an activity away from the home. Respite care can be given by a trained professional, agency, babysitter, friend, or family and may cost money or can be given as a free service. Abelson (1999) reported that parents of children with developmental disabilities generally thought that the availability of respite care services would improve their overall family functioning. Respite care may provide a needed break for the parents as well as for the child with the disability (Abelson, 1999). If parents of a child with an ASD are able to take some breaks from their care giving roles, they may improve the quality of their marriage.

In their longitudinal research, Mullins, Aniol, Boyd, Page, and Chaney (2002) studied processes in families with children with a developmental disability over three time periods: at admission to respite care, at discharge from respite care, and six months following discharge. Respite care for brief amounts of time helped alleviate parental stress and psychological distress. After examining the data from time one to time two and from time two to time three, stress dramatically decreased for the parents over the three waves of data, and they functioned better and experienced less depression. They evaluated the families again six months after ending respite care. The lower stress levels were sustained over a six month period, but at six months, stress levels for both parents had returned to their baseline state. They suggested that more research was needed to evaluate the long-term effects of brief respite care services. Based on

measures of psychological assessment, the researchers claimed that respite care increased both parents' psychological functioning and well-being.

There are several difficulties with the Mullins, et al. (2002) study. There was a small group of participants (39 parents), most of whom were mothers, with a few grandmothers and fathers. The respite care was not provided at home, but rather the child was taken from the home and placed in inpatient care for 3-7 days, which is not a typical respite care service delivery model. Also, the authors did not state whether any children with an ASD were included in the study (Mullins, et. al, 2002).

Family and marital difficulties for couples who have a child with an ASD may contribute to couples having greater difficulty finding time for each other. Stresses and strains of caring for their child may make it difficult for parents to focus on each other and their relationship. The severity of the child's challenging behaviors can take a toll on the parents (Osborne & Reed, 2010). It could also be that mothers, who are more likely to feel burdened by the care of a child with an ASD, experience increased stress, which leads to greater irritability and more distressed marital interaction. Perhaps these couples exhibit more marital distress when they are not able to get a break. If ways could be found to help couples find more time to spend with each other and focus on their relationship, the marital satisfaction of parents of a child with an ASD may not be so affected (Abelson, 1999). Respite care is a positive option that might decrease parents' stress levels and may increase marital quality.

Statement of the Problem

Although some research studies have investigated how respite care affects families raising children with an ASD, the author could find no empirical studies examining the direct

effects of respite care on families with a child with an ASD and how respite care is related to marital processes. Many researchers have investigated how stress is linked to a couple's marriage and suggested that respite care may help reduce stress in marriage, but no studies have examined whether respite care actually does this. In addition, no studies have examined how resources in the form of daily uplifts may be related to quality of marriage. Furthermore, studies need to be conducted to determine if respite care is directly related to marital quality.

Statement of Purpose

The purpose of this study was twofold: 1) To examine the relationship between respite care and quality of marriage for couples with a child with an ASD, with wife and husband stress as potential mediating variables, and 2) To examine husband and wife daily uplifts as potential mediating variables.

Research Questions

This study addressed the following research questions:

1. Is there a relationship between respite care and marital quality of parents of children with an ASD spectrum disorder?
2. Does stress of the father and the mother and perceived uplifts of the father and mother mediate the relationship between respite care and marital quality?

Hypotheses

1. There will be a significant positive relationship between the amount of respite care and relationship quality for both husbands and wives.

2. There will be a significant negative relationship between husband's stress and husband's and wife's perception of marital quality. There will be a significant negative relationship between wife's stress and husband's and wife's perception of marital quality.
3. There will be a significant negative relationship between the amount of respite care and individual's stress for both husband and wife.
4. There will be a significant positive relationship between the amount of respite care and the individual's daily uplifts for both husband and wife.
5. There will be a significant positive relationship between husband's uplifts and husband's and wife's perception of marital quality. There will be a significant positive relationship between wife's uplifts and husband's and wife's perception of marital quality.
6. Husband and wife individual stress will significantly mediate the relationship between amount of respite care and marital quality.
7. Husband and wife individual uplifts will significantly mediate the relationship between amount of respite care and marital quality.

Method

Participants and Settings

After receiving approval from the Institutional Review Board, families were initially contacted by sending a letter home with children who attended classes for students with special needs, specifically for children with an Autism Spectrum Disorder (ASD) (See Appendix B for

copy of the letter). Representatives in Alpine School District, Nebo School District, Provo School District, Kids on the Move, Wasatch Mental Health Giant Steps, and Clear Horizons were contacted to receive permission to send contact letters home with the children in classes for students with an ASD. When permission was obtained from the schools and districts, letters were sent to parents inviting them to participate in the study. The inclusion criteria included: (a) the parents have a child with an ASD as evidenced by either an IEP classification or a medical diagnosis, and (b) the parents are married to each other.

Contact was also made with organizations including the Utah Parent Center, Utah Coalition for Autism, and other websites or facilities who would advertise this study. A link would be available on their websites for couples to complete the measures. Other organizations that have links to Autism information for parents, such as Autism Speaks, were contacted to receive permission to advertise the study through their website and contacts.

One hundred and one couples (101 husbands and 101 wives) completed the questionnaire. As shown in Table 1, the average age of husbands was 39.21 ($SD = 6.89$), and the average age of wives was 38.01 ($SD=7.04$). The average length of marriage for the couples was 11.89 years (3.12 years). The average number of children was 3.09 ($SD = 1.65$). Husbands reported an annual household income of \$55,353 ($SD = \$18,649$), and wives reported \$55,349 ($SD = \$18,713$). Approximately 96% of the couples were both biological parents of the child diagnosed with an ASD, and 4% were remarried with one of the parents being the biological parent of the child diagnosed with an ASD. In terms of race, 82.2% of the husbands were White, 8.9% were Hispanic or Latino, 5.0% were African American, 1% were Native Hawaiian/Pacific Islander, and 3.0% reported being of another racial group. Of the mothers, 86.1% were White,

6.9% were Hispanic or Latino, 4% were African American, and 3% were of another race. The majority of the participants were from the Rocky Mountains (53.1%) with 11% from the West Coast, 14.9% from the South, 6.6% from the Southwest, 5.6% from the Northeast, 4.4% from the Mid Atlantic, and 4.4% from the Midwest. Regarding their marriage relationship, 14.8% of husbands and 16.7% of wives reported distressed marriages as determined by the Revised Dyadic Adjustment Scale cut off of 48 (Busby, Christensen, Crane, & Larson, 1995).

Table 2 shows the demographic characteristics of children diagnosed with an ASD, broken down by diagnosis of Autism, Asperger Syndrome, and Pervasive Developmental Disorder - Not Otherwise Specified. There were 34 females and 67 males with ages ranging from 1-33 years for children diagnosed with an ASD. The average age of the diagnosed children was 7.66 years ($SD = 3.42$). Approximately 59% of the parents reported receiving some type of respite care. Of the types of respite care, 29.6% was provided by grandparents, 13.0% was provided by extended family, 29.6% was provided by a babysitter, 20.4% was provided by a community agency, and 7.4% was provided by a combination of the above. For those who had respite care, parents were asked about their satisfaction with the care, and 88.6% reported being satisfied with their respite care provider.

Measures

Two latent variables called husband marital quality and wife marital quality were created using three indicators for each variable, the Revised Dyadic Relationship Scale (Busby, et al., 1995), and two subscales (anxious and avoidant attachment) from the *Revised Experiences in Close Relationships Questionnaire* (Fraley, Waller, & Brennan, 2000). Two latent variables called husband stress and wife stress were created with two indicators, severity and frequency,

which are subscales of *the Hassles and Uplifts Scale*; two latent variables called husband uplifts and wife uplifts were created with two indicators, intensity and frequency, the uplifts subscales of the same measure (Lazarus & Folkman, 1984).

Revised Dyadic Adjustment Scale, RDAS (Busby, et al., 1995). Each partner in the couple completed the RDAS, a 14-item questionnaire about the quality of a committed relationship. The RDAS consists of three subscales: cohesion, consensus, and stability. For the consensus subscale, participants use a 6-point Likert scale ranging from 0 (Always Disagree) to 5 (Always Agree) to answer six items. Examples of questions from this subscale include “Please indicate the extent of agreement between you and your partner on making major decisions,” and “Please indicate the extent of agreement between you and your partner on sex relations.” The stability subscale consists of four items which each partner answers using a 6-point Likert scale that ranges from 0 (All the time) to 5 (Never). Examples of items include, “Do you ever regret that you married?” and “How often do you and your mate ‘get on each other’s nerves’?” The cohesion subscale consists of four items that are answered using a 6-point Likert scale ranging from 0 (Never) to 5 (more often than once a day). Examples of items on this subscale include “How often do you and your mate engage in outside interests together?” and “How often do you and your mate calmly discuss something?” The answers to the 14 items on the three subscales are summed yielding a score that can range from 0 to 70 with 48 being the cut off score for discriminating distressed from non-distressed couples (Busby, et al., 1995). Higher scores indicate higher perceived marital quality.

The reliability of the RDAS was determined by dividing the items in half and giving each half to respondents (Busby, et al., 1995). The split half reliability coefficient for the entire scale

was .94. Validity of the RDAS has been established in several ways. Factor analyses were conducted using LISREL (Joreskog & Sobom, 1989) and factor loadings were robust and ranged from .74 to .97. Concurrent validity was established by correlating scores from the Marital Adjustment Test (MAT; Locke & Wallace, 1959), which resulted in a coefficient of .68, which was better than the correlation of the Dyadic Adjustment Scale and the MAT. Predictive validity was established by determining how well the RDAS overall score predicted accurate membership in distressed or non-distressed couples. The RDAS had 86% accuracy in predicting group membership. It appears that the RDAS has adequate reliability and validity for research.

Revised Experiences in Close Relationships Questionnaire (Fraley, et al., 2000).

This measure assesses the degree of attachment in a romantic relationship. It is made up of two subscales, anxiety and avoidance, both with 18 items. Both husbands and wives answered the items using a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). Examples from the anxious attachment subscale include “I am afraid I will lose my partner’s love” and “I often worry that my partner does not really love me.” Examples from the avoidant attachment subscale include, “I find it difficult to allow myself to depend on my partner,” and “I prefer not to show my partner how I feel deep down.” The answers to the 18 items on each subscale are summed so total scores can range from 18 to 126. Fraley et al. (2000) found inter-item reliability to be .91 for the anxious attachment subscale and .90 for the avoidant attachment subscale. In terms of validity, the anxious attachment scale was shown to be correlated at .74 with the adult attachment interview (Main & Cassidy, 1988), and the avoidant attachment scale was shown to be correlated at .68 with the avoidance section in the adult attachment interview.

Hassles and Uplifts Scale, HUS (Lazarus & Folkman, 1984). Using a Likert scale from

0 (not at all) to 4 (extreme), participants indicated how much of a daily hassle and how much of a daily uplift each of the 53 items is. Examples of items include “Work,” “Money,” and “Extended Family.” A frequency score was calculated by counting the number of items that have a score greater than zero. An intensity score was calculated by summing the answers to all items. The frequency score and the intensity score were the two indicators to create a latent variable called stress for each partner in the relationship. The intensity and frequency score for the daily uplifts was treated the same way. The intensity scores can range from 0 to 212, and the frequency scores can range from 0 to 53.

Because the HUS relies on the appraisal of the individual to determine the severity of a given stressful event, as well as whether the person perceives an event as an uplift, it has a relatively high degree of face and content validity. In addition, a factor analysis of the HUS generated eight factors. Factor loadings ranged from .27 to .85. Items that had a low factor loading or did not load on a factor were dropped in the latest version of the scale used in this study leaving 53 items in the current version. The HUS was found to correlate with both illness and distress. Touliatos, Perlmutter, and Straus (1990) reported the test/retest reliability to be $r = .79$ for the hassles items and $.82$ for the uplift items.

Respite care. Respite care was measured with two questions. The first question asked respondents to indicate how much respite care they receive in hours and minutes Monday-Friday in a typical week. Respite care was defined as “planned care for the child with autism to provide relief to the permanent caregiver.” The second question asked how much respite care they receive on typical weekend days, Saturday-Sunday. The answers to these two questions were summed to create a total amount of hours for respite care. In cases where more than one child

was receiving respite care, the researchers examined whether the reported hours were the same for each child. If so, the hours for the second child were not treated as additional respite hours. When the parent reported additional hours for a second child that were different from the hours for the first child, those hours were added to the total sum. Since both husbands and wives responded to this question, their respective sum of hours and minutes of respite care were the two indicators for the latent variable, amount of respite care.

The questionnaire also included demographic questions asking about age, length of marriage, annual house hold income, education level of parents, race, number of children, and age, gender, and medical diagnoses of the child/or children with special needs. These variables were used as control variables in the analysis.

Procedures

The letters instructed parents to contact the researcher by phone, email, or by returning a portion of the letter giving permission with their contact information. Each family was contacted and given a packet by email, web link, mail, or hand delivery. The packets for the families included instructions, a background questionnaire, marital quality measures, stress measures, and the respite care measure. Each partner in the couple was instructed to fill out their questionnaires independently and return them separately through email, web link, or mail. If the packet was hand delivered, it included separate return envelopes, one for the husband and one for the wife, to be mailed by the couple or collected by the researcher.

Research Design

This study was a multivariate correlational design using AMOS 16 (SPSS, 2009) to

perform structural equation modeling. An Actor Partner Independence Model or APIM (Kenny Kashy, Cook, & Simpson, 2006) was used to estimate the effects of the independent variable, amount of respite care on the dependent variables, husband and wife relational quality. The indirect paths through husband and wife daily stress were also estimated. The APIM included the actor effects, or the paths between the same person's variables (e.g., amount of respite care to husband's relational quality as well as through husband's daily stress). Likewise, the same relationships were examined for the wife. The partner effects are the influences of the partner's variables on their spouse (e.g., amount of respite care predicting husband's relational quality filtered through the wife's daily stress and the partner paths for the husband's daily stress to the wife's relationship quality). A second APIM model was also created where husband daily uplifts and wife daily uplifts were substituted for husband stress and wife stress as potential mediating variables.

As can be seen in Figure 1, the error terms for the husband's and wife's RDAS and for the husband's and wife's attachment scores were correlated since they were both reporting on their marriage.

Statistical Analysis

The first step in the analysis was to examine descriptive statistics. Means, standard deviations, and correlations between all variables were calculated. In the next step, confirmatory factor analysis was used to determine factor loadings for indicators on each latent variable for both the model with stress as the mediator and the second model with uplifts as the mediator. Factor loadings for the measures of latent variables ranged from .81 to .99 as can be seen in Figures 2 and 3. Then, unstandardized and standardized beta coefficients were calculated to

determine the strength of the direct and indirect paths in both structural models, one with husband stress and wife stress as mediating variables and one with husband uplifts and wife uplifts as potential mediating variables. Sobel tests were calculated to determine if the mediation effects were statistically significant.

Results

Correlations and Means

Table 3 shows the correlations, means, and standard deviations for all measured variables in the study. The correlation between the wives' report of respite hours and husbands' report of respite hours was .99 meaning that they were extremely similar in reporting respite hours. The correlation of both husbands' and wives' respite hours were significantly negatively correlated with their respective reports of stress. For example, the correlation between wives' respite hours and wives' severity of stress was $-.34$ ($p < .001$) and wives' frequency of stressors was $-.25$ ($p < .001$). Husbands' report of respite hours was also significantly negatively correlated with husbands' severity of stress ($-.27$, $p < .001$) and husbands' frequency of stressors ($-.26$, $p < .001$). Amount of respite care was also significantly related to all measures of marital quality. For example, the correlation of amount of respite care for wives was positively correlated with the Revised Dyadic Adjustment score ($.39$, $p < .001$), and negatively correlated with wives' anxious attachment ($-.35$, $p < .001$) and with avoidant attachment ($-.39$, $p < .001$). For husbands, amount of respite care was negatively correlated with their Revised Dyadic Adjustment Scale score ($.39$, $p < .001$) and negatively correlated with their anxious attachment ($-.29$, $p < .001$) and their avoidant attachment ($-.30$, $p < .001$). Stress for both husbands and wives was highly correlated with

measures of marital quality.

For wives, severity and frequency of stress were negatively correlated with Revised Dyadic Adjustment ($-.68, p<.001$; $-.39, p<.001$ respectively). Wives' frequency and severity of stress were positively correlated with their anxious attachment ($.58, p<.001$; $.41, p<.001$ respectively) and with their avoidant attachment ($.59, p<.001$; $.40, p<.001$ respectively). For husbands, severity and frequency of stress were negatively correlated with Revised Dyadic Adjustment ($-.66, p<.001$; $-.47, p<.001$ respectively). Husbands' frequency and severity of stress were positively correlated with their anxious attachment ($.50, p<.001$; $.38, p<.001$ respectively) and with their avoidant attachment ($.51, p<.001$; $.40, p<.001$ respectively). Control variables, including husbands' and wives' age, education, race, income, length of marriage, and number of children, were not significantly correlated with amount of respite care, husbands' and wives' stress and uplifts, and the three measures of marital quality.

Amount of respite care was positively correlated with both husbands' and wives' perceived uplifts ($.29, p<.001$ for husbands' uplifts intensity; $.32, p<.001$ for husbands' uplifts frequency; $.25, p<.01$ for wives' uplifts intensity; $.21, p<.01$ for wives' uplifts frequency). Wives' reports of uplifts were also significantly related to their reports of marital quality ($.44, p<.001$ for wives' uplifts intensity with RDAS; $.47, p<.001$ for wives' uplifts frequency with RDAS; $-.32, p<.001$ for wives' uplifts intensity with anxious attachment; $-.35, p<.001$ for wives' uplifts frequency with anxious attachment; $-.43, p<.001$ for wives' uplifts intensity with avoidant attachment; $-.43, p<.001$ for wives' uplifts frequency with avoidant attachment).

Husbands' reports of uplifts were positively related to husbands' marital quality scores ($.53, p<.001$ for husbands' uplifts intensity with RDAS; $.46, p<.001$ for husbands' uplifts

frequency with RDAS; $-.40, p < .001$ for husbands' uplifts intensity with anxious attachment; $-.47, p < .001$ for husband's uplifts frequency with anxious attachment; $-.41, p < .001$; $-.51, p < .001$ for husbands' uplifts intensity and frequency with avoidant attachment). Husbands' and wives' scores for stress severity and frequency were generally negatively correlated with their scores for uplifts intensity and frequency ($-.23^{**}, p < .01, -.10, n.s.$ for wives' stress intensity with uplifts intensity and frequency; $-.28, p < .001$; $.01, ns$ for wives' stress frequency with uplifts intensity and frequency; $-.39, p < .001, -.29, p < .001$ for husbands' stress severity with uplifts intensity and frequency; $-.37, p < .001, -.16, p < .05$ for husbands' stress frequency with uplifts intensity and frequency).

Wives reported mean respite hours of 6.59 per week ($SD=9.54$) and husbands reported mean respite hours of 6.32 per week ($SD=9.18$). Wives' and husbands' mean severity stress scores were 107.09 ($SD=28.44$) and 108.98 ($SD=31.26$) respectively. In terms of the average number of times husbands and wives endorsed items as stressful (stress frequency scores), wives' mean score was 31.40 ($SD=9.94$), and husbands' mean score was 31.28 ($SD=11.51$). This indicates that both husbands and wives were endorsing slightly over 60% of the 53 items as stressful, and the severity scores were relatively high. In terms of the average number of times husbands and wives endorsed items as uplifts (uplift frequency scores), wives reported a mean of 28.51 ($SD=9.78$), and husbands reported a mean of 29.69 ($SD=14.29$). Husbands' and wives' mean uplifts intensity scores were 101.91 ($SD=27.95$) and 102.64 ($SD=24.18$) respectively. Husbands' and wives' Dyadic Adjustment Scales score means were 58.45 ($SD=12.73$) and 58.87 ($SD=12.69$) respectively. Mean anxious attachment for wives was 47.61 ($SD=26.19$) and mean avoidant attachment was 51.27 ($SD=28.05$). Mean anxious attachment for husbands was 51.34

(SD=28.40) and mean avoidant attachment was 51.57 (SD=26.08). As reported earlier, 14.8% of husbands and 16.7% of wives were in the distressed marriage range as determined by RDAS scores (Busby, et al., 1995).

Measurement and Structural Model Results

Figure 2 shows the factor loadings for each measured variable on their respective latent variables, as well as the standardized and unstandardized Beta coefficients for each structural path in the model with husband and wife stress as potential mediators. The overall fit indices showed that the hypothesized model was a good fit to the actual data. The Chi Square was insignificant ($X^2=38.94$, $df=38$, $p=.47$); the Comparative Fit Index (CFI) was well above .95 (CFI=.998), and Root Mean Square Error of Approximation (RMSEA) was less than .05 (RMSEA=.017), and the Standardized Root Mean Square Residual (RMSR) was less than .08 (RMSR=.032). The overall R^2 for wives' marital quality was .51, and it was .42 for husbands' marital quality, meaning that the overall model explained 51% of the variance for wives' marital quality and 42% of the variance for husbands' marital quality.

Figure 3 shows the results for the model with husband and wife uplifts as potential mediators. As was true for the first model, the overall fit indices showed that the hypothesized was .994 with an *RMSEA* of .021 and an *SMSR* of .03. The overall R^2 for this second model was .28 for wives and .33 for husbands.

Hypothesis 1 results: Amount of respite care and marital quality. Hypothesis 1 stated that there would be a significant positive relationship between amount of respite care and relationship quality for both husbands and wives. As shown in Figure 2, there was a significant positive relationship between amount of respite care and marital quality for husbands ($\beta=.41$,

$p < .001$). There was also a significant positive relationship between amount of respite care and wife marital quality ($\beta = .56$, $p < .001$). The unstandardized Beta for husbands was 6.12 meaning for every hour increase in respite care husbands' relationship quality increases 6.12 units. The wives' unstandardized Beta was 3.79 meaning for every hour increase in respite care her relationship quality scores increased by 3.79. As can be seen in Figure 3, similar results were found for the analysis of the model with uplifts as potential mediating variables ($\beta = .57$, $p < .001$ for wives and $\beta = .47$, $p < .001$ for husbands). Therefore, hypothesis 1 was supported.

Hypothesis 2 results: Stress and marital quality. Hypothesis 2 stated that there would be a significant negative relationship between husbands' stress and husbands' and wives' marital quality and there would be a significant negative relationship between wives' stress and husband and wives' marital quality. Figure 2 shows that the standardized Beta for the relationship between husbands' daily stress and husbands' marital quality was $-.15$ ($p < .05$). The relationship stress between husbands' daily stress and wife marital quality was not significant ($\beta = -.12$). There was a significant negative relationship between wife daily stress and wife marital quality ($\beta = -.35$, $p < .001$), and there was a significant negative relationship between wife daily stress and husband marital quality ($\beta = -.18$, $p < .05$). The unstandardized Beta for the relationship between husband daily stress and husband marital quality was $-.74$, meaning for every one unit increase in husband daily stress, marital quality decreases by $.74$ unit. The unstandardized Beta for the relationships between wife daily stress and wife marital quality was -1.04 , meaning that for every one unit increase in wife daily stress her relationship quality decreases by 1.04 unit. The unstandardized Beta for the relationship between wife daily stress and husband relationship quality was $-.07$, which means for every one unit increase in wife daily stress, husband marital

quality decreases by .07 unit, even when controlling for the relationship between husband daily stress and husband relationship quality. Therefore, hypothesis 2 was confirmed for wives and only partially confirmed for husbands. For wives there was an actor and partner effect of wife daily stress on respective marital quality, but for husbands there was only an actor effect and no significant partner effect.

Hypothesis 3 results: Amount of respite care and stress. Hypothesis 3 stated that there would be a significant negative relationship between the amount of respite care and individual stress for husbands and wives. As seen in Figure 2, there was a significant negative relationship between amount of respite care and wife daily stress ($\beta = -.32, p < .001$) and between the amount of respite care and husband daily stress ($\beta = -.30, p < .001$). The unstandardized Beta for wives was -5.05, and -5.60 for husbands. This means for every hour increase in respite care, wife daily stress decreases by 5.05 units and husband daily stress decreases by 5.60 units. Therefore, hypothesis 3 was supported for both husbands and wives.

Hypothesis 4 results: Amount of respite care and uplifts. Hypothesis 4 stated that there would be a significant positive relationship between husband and wife reported amount of respite care and husbands' and wives' reported uplifts. As can be seen in Figure 3, there was a significant positive relationship between amount of respite care and husband uplifts ($\beta = .37, p < .001$) and wife uplifts ($\beta = .21, p < .01$). The unstandardized beta for husbands was 5.60, meaning that for every hour increase in respite care husband uplifts increased by 5.6 units, as compared to wives whose increase is only 2.05. Hypothesis 4 was supported for both husbands and wives.

Hypothesis 5 results: Uplifts and marital quality. Hypothesis 5 stated that there would

be a significant positive relationship between husband and wife uplifts and husband and wife marital quality (actor effects) and that there would be significant paths from husbands' uplifts to wives' marital quality and vice versa (partner effects). As can be seen in Figure 3, husband uplifts was positively related to husband marital quality and wife marital quality ($\beta=.46$, $p<.001$; $\beta=.38$, $p<.001$ respectively). Wife uplifts was also positively related to both her and his marital quality ($\beta=.30$, $p<.001$; $\beta=.27$, $p<.01$ respectively). Therefore, hypothesis 5 was confirmed for both husband and wives and for both actor and partner effects.

Hypothesis 6 results: Stress as mediator between respite care and marital quality.

Hypothesis 6 stated that husbands' and wives' daily stress would significantly mediate the relationship between amount of respite care and marital quality (related to Figure 2). A Sobel Test showed that wife daily stress significantly mediated the relationship between amount of respite and wife marital quality (Sobel=8.39, $p<.001$). Wife daily stress was not a significant mediator of the relationship between amount of respite and husband marital quality (Sobel=.35, $p=.37$). A Sobel Test showed that husband daily stress was a significant mediator between amount of respite and husband marital quality (Sobel=5.23, $p<.001$). Of course, husband daily stress did not significantly mediate the relationship between amount of respite and wife marital quality since there was not a significant relationship between husband daily stress and wife marital quality. Therefore, hypothesis 6 was partially supported in that husband and wife respective stress mediated the relationship between the amount of respite and their respective relationship quality, but did not mediate between respite care and partner's relationship quality.

Hypothesis 7 results: Uplifts as mediator between respite care and marital quality.

Hypothesis 7 stated that husband uplifts and wife uplifts would be significant mediating

variables between amount of respite care and husband and wife marital quality. Four Sobel Tests were performed for each of the mediating paths in the model shown in Figure 3, and the actor effects paths were statistically significant (8.81, $p < .001$ for path through wife uplifts to her marital quality; 21.10, $p < .001$ for the path through husband uplifts to his marital quality) as well as the partner effects paths (8.21, $p < .001$ for the path through wife uplifts to husband marital quality; 18.66, $p < .001$ for the path through husband uplifts to wife marital quality). Therefore, hypothesis 7 was fully supported for both actor and partner effects.

Discussion

This study examined the role of husband and wife stress as possible mediating variables of the relationship between respite care and quality of marriage for couples with a child with an ASD. The following sections of the discussion will compare the findings of this study with published findings from other empirical studies, explore possible meanings of the findings, examine limitations of this study, and identify implications of the findings of this study for further research and for practitioners.

Reflections on the Relationship of Respite Care and Marital Quality

Abelson (1999) hypothesized that respite care would help improve family functioning. The findings of this current study confirm Abelson's hypothesis because the amount of respite care was related to marital quality for both husbands and wives. Particularly surprising was the finding that just one hour increase in respite care was related to an increase of 6 to 7 points in marital quality, which is approximately one half of a standard deviation increase. For example, if a husband or a wife scored 43 on the Revised Dyadic Adjustment Scale, one hour of respite

care would raise the score by six points moving them to the nondistressed range. This finding is also consistent with Higgins et al. (2005), who found that in families with a child diagnosed with an ASD, couples had lower marital happiness. The finding that respite care is related to marital quality offers a solution to couples who are parenting a child with an ASD. It may give such couples hope that their marriage can be strengthened.

Reflections on the Relationship of Respite Care and Stress

Mothers of a child with an ASD have higher levels of parenting stress and psychological distress (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009). Given the findings of this study, it is logical to assume that mothers' parenting stress and psychological distress would decrease by using respite care, and that mothers' uplifts would increase. Kersh, Hedvat, Hauser-Cram, and Warfield (2006) found that in both mothers and fathers of a child with a developmental disability, greater marital quality predicted lower parenting stress and fewer depressive symptoms. Since marital quality is an important resource for parents with a child with an ASD, the finding that amount of respite care is positively related to marital quality offers parents a strategy for increasing and maintaining marital quality.

Mullins, Aniol, Boyd, Page, and Chaney (2002) found that respite care lowered stress for parents, consistent with the findings of this study that amount of respite care was negatively related to both wife and husband stress. In the Mullins, et al. study, parents' stress was measured when the child was admitted to inpatient respite care and measured again at discharge. At discharge the parents' stress was significantly decreased, but at a six month follow-up the parents had returned to high stress levels indicating the need for respite care. The respite offered in the Mullins, et al. study was unusual because children were placed in a hospital setting 24 hours a

day for several days. Respite care, as measured in this study, was a more natural respite care offered each week, and the type of respite care most typically offered by family members. Results imply that respite care on a regular basis is related to decreased stress. Mullins, et al. (2002) did not include any measure of parental resources or perceptions of uplifts in their study. A contribution of the current study is the finding that respite care is also positively associated with uplifts, especially for fathers. Additionally, appears that both wives and husbands endorse people and events as both stressors and uplifts with wives endorsing 62% of items and husbands endorsing 58% of items as being both a stressor and an uplift. For example, 88% of wives and 82% of husbands felt that their children were both a stressor and an uplift.

Reflections on the Relationship of Uplifts and Marital Quality

The strong relation between husband uplifts and marital quality was surprising. Burr and Klein (1994) called for more attention to resources and people's perception of resources in stress research. In this study, uplifts were examined to step up to this call. It appears that husband uplifts are stronger mediators than wife uplifts in the relationship between respite care and both husband and wife marital quality whereas, wife stress was a stronger mediator between respite and wife and husband marital quality.

Reflections on the Mediating Roles of Stress and Uplifts

The finding that stress and uplifts only partially mediated the relationship between amount of respite care and marital quality means that there are perhaps other processes that mediate these relationships. Perhaps the fact that respite care potentially allows the couple to spend time together is one of these other processes. Respite care may also enable a parent to

accomplish chores and other duties, leaving more time for the couple to spend together at a later time. Regarding uplifts, husbands and wives may have sources of uplifts outside of their parenting context. Since this study was only correlational, parents who perceive more uplifts in their lives might be more likely to seek respite care services. Only a longitudinal study could provide an answer.

Respite care might just give the parents a break from the child who misbehaves, potentially decreasing the stress of the parents. Brobst et al. (2009) discovered children's behavior is related to the stress of parents. When parents' stress is reduced, parents are likely to better cope with their children's behaviors better, which leads to overall higher family functioning. Families with children diagnosed with an ASD also have a higher level of caregiver burden (Lee et al., 2008), which, according to the findings of this current study, might be alleviated through respite care if caregiver burden is related to stress. Liptak, Stuart, and Auinger (2006) hypothesized that a factor related to couples' stress is financial since raising children with an ASD was found to be more expensive than raising children without an ASD. Randall and Parker (1999) demonstrated that families with a child diagnosed with an ASD had increased parental stress, but according to our findings this stress could be reduced with the use of respite care.

Reflections on Stress of Mothers Compared to the Stress of Fathers

Contrary to our findings, Tehee, Honan, and Hevey (2009) found that mothers reported more stress than fathers. Our findings that mothers' and fathers' stress is similar may be related to the fact that stress was measured by Daily Hassles, rather than specific parenting stress. Wives also reported slightly more uplifts than husbands; however, these differences were not

statistically significant.

Limitations

There were several limitations related to this study. This sample was not a random representative sample so caution should be urged in generalizing the findings to every couple living in the United States. The couples were volunteers who found the invitation to participate in the study through their child's special education class, autism related websites, or organizations serving children with autism. Another limitation is that the sample was mostly Caucasian, so findings cannot be generalized to couples of other races. A third limitation is that the study was questionnaire-based where the parents were expected to take the questionnaire separately without communicating with each other, but there was no monitoring to ensure that questionnaires were completed independently. This study was cross-sectional so no inferences can be made about causation among the variables. For example, one cannot assume that amount of respite care is causally related to marital quality. An additional limitation may be related to the measure of amount of respite care. Because there are no generally accepted, standardized measures of respite care, the self-report method used in this study may have certain biases related to self-reporting.

Implications for Further Research

The findings of this study raise several questions. One question is whether increasing the amount of respite care in couples would actually raise their marital quality. Intervention studies using controlled respite care as the intervention would help answer this question. Several other questions need to be answered. Is it the quality of respite care or quantity of respite care that

makes a difference? Are relatives or trained professionals better for respite care providers? What stressors does respite care relieve? What is the best “dosage” of respite care-how much time should be involved and how often should it occur? Is it possible that an on-respite off-respite of some combination will be as effective as respite care every week? Another area of research that would be useful is an intervention study of in-home respite care where either the parent leaves or the children are taken outside of the home for a reasonable amount of time. Studies are needed that control for what husbands and wives do during respite care. Is there a difference between couples who spend time together during respite care and those who use the time to complete individual tasks? Does spending time together make a difference or simply just having a break from the children or the child with an ASD make a difference?

Implications for Policy Makers and Practitioners

The findings of this study are relevant for policy makers. Formal respite care is often not available to parents of a child diagnosed with an ASD, either because families cannot afford it, or because skilled care is unavailable. Informal respite care, such as that provided by family and babysitters, may also be limited due to complex family issues and the lack of qualified caregivers. The findings of this indicate that funding to provide more respite care for parents of a child with an ASD could improve the quality of life by preserving marital quality and reducing parents’ stress, as well as increasing their uplifts.

There are many implications from these findings that are important to special educators and therapists who work with families with a child diagnosed with an ASD. It is important for practitioners to find a way for families to receive respite care. If parents were required to receive respite care as part of their child’s special education and funding sources made available to those

who cannot afford it, parents might experience a reduction of stress as well as an increase in uplifts and increase their marital quality. Respite care should be provided so it is not a financial burden to these families since having a child diagnosed with an ASD is already a possible financial stressor. Respite care needs to be provided by people that can be trusted and trained so families feel comfortable in leaving their child diagnosed with an ASD. While many special education programs offer parenting education to help parents better cope with their child's behaviors, the findings of this study imply that respite care is also a way of helping parents reduce individual stress. Professionals could be used to train family members who are willing to give respite care so the family members can be confident in how to handle behaviors and typical issues related to an ASD.

Conclusion

The findings of this study showed that amount of respite care is related to marital quality for both husbands and wives who have a child diagnosed with an ASD. It appears that mechanisms through which respite care affects marital quality is through the individual levels of stress and uplifts of both mothers and fathers. Respite care helps reduce stress which, in turn, affects marital quality. A lack of respite care was related to higher stress of both mothers and fathers. Increased respite care was related to higher uplifts of both parents. Policy makers should consider how providing respite care affects the quality of family life for those who have a child diagnosed with an ASD.

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Table 1

Demographic Characteristics of Husbands and Wives (N=101 husbands, 101 wives)

Variables	Husbands Mean (SD)	Wives Mean (SD)
Age	39.21 (6.89)	38.01 (7.04)
Length of Marriage	11.89 (3.12)	11.89 (3.12)
Number of Children	3.09 (1.65)	3.09 (1.65)
Annual Household Income	\$55,353 (\$18,649)	\$55,349 (\$18,713)
		Percentages
Relationship Status		
Both biological Parents of ASD Child	96.7%	96.7%
Remarried, living w/ biological ASD child	3.3%	3.3%
Distressed (determined by RDAS cut off of 48)	14.3%	15.4%
Education		
Less than High School	0.0%	0.0%
High School Graduate	13.4%	10.8%
Completed Some College	26.5%	32.4%
Bachelor's Degree	43.5%	43.9%
Master's Degree	12.5%	8.8%
Doctorate/Professional Degree	5.1%	4.1%
Race		
Hispanic or Latino	8.9%	6.9%
Black or African American	5.0%	4.0%
Native Hawaiian/Pacific Islander	.90%	0.0%
White	82.2%	86.1%
Other	3.0%	3.0%
Geography		
Mid Atlantic	4.4%	4.4%
Midwest	4.4%	4.4%
Northeast	5.6%	5.6%
Rocky Mountains	53.1%	53.1%
South	14.9%	14.9%
Southwest	6.6%	6.6%
West Coast	11.0%	11.0%

Table 2

Demographic Characteristics of Children with Autism Spectrum Disorder (N=91; 34 females; 67 males)

Variables	Diagnosis					
	Autism		Asperger		Pervasive Developmental Disorder-NOS	
	Male Number	Female Number	Male Number	Female Number	Male Number	Female Number
Birth Order of Child						
1 st	27	16	5	2	7	3
2 nd	17	3	1	1	0	2
3 rd	4	3	1	1	1	2
6 th	3	1	0	0	0	0
Gender	51	22	7	5	8	7
Age Mean (S.D.)	7.26 (3.30)	7.89 (4.73)	10.86 (3.02)	10.80 (2.39)	7.00 (2.83)	7.67 (3.39)
% Receiving Respite	56%	46.9%	28.6%	80.0%	87.5%	85.7%
Type of Respite						
Grandparents	7	6	0	3	1	3
Extended Family	6	0	1	0	0	0
Babysitter	8	5	1	0	4	0
Community Agency	6	1	0	0	2	2
Combination	3	0	0	1	0	0

Table 3

Means, Standard Deviations, and Correlations for All Measured Variables (continued on next page)

	1	2	3	4	5	6	7	8	9	10	11	12
1.WRespite Hrs.	1.0											
2.HRespite Hrs.	.99***	1.0										
3.WStress Severity	-.34***	-.35***	1.0									
4.WStress Frequency	-.25***	-.28***	.83***	1.0								
5.HStress Severity	-.26***	-.27***	.74***	.62***	1.0							
6.HStress Frequency	-.25***	-.26***	.50***	.59***	.76***	1.0						
7.WRDAS	.39***	.32***	-.68***	-.49***	-.60***	-.41***	1.0					
8.WAnx Attachment	-.35***	-.33***	.58***	.40***	.52***	.41***	-.73***	1.0				
9.WAvoid Attachment	-.39***	-.40***	.52***	.41***	.53***	.43***	-.62***	.72***	1.0			
10.HRDAS	.42***	.39***	-.59***	-.40***	-.66***	-.47***	.78***	-.63***	-.69***	1.0		
11.HAnx Attachment	-.39***	-.29***	.44***	.27***	.51***	.40***	-.67***	-.76***	.67***	-.77***	1.0	
12.HAvoid Attachment	-.30***	-.30***	.47***	.32***	.53***	.42***	-.74***	.56***	.74***	-.81***	.79***	1.0
13.WUplifts Intensity	.25***	.23**	-.23**	-.10	-.30***	-.25**	.44***	-.32***	-.43***	.45***	-.38***	-.47***
14.WUplifts Frequency	.21**	.24**	-.28***	.01	-.34***	-.14	.47***	-.35***	-.42***	.44***	-.39***	-.46***
15.HUplifts Intensity	.30***	.29***	-.26***	-.23**	-.39***	-.29***	.45***	-.36***	-.44***	.53***	-.40***	-.47***
16.HUplifts Frequency	.33***	.32***	-.26***	-.14	-.37***	-.16*	.48***	-.37***	-.41***	.46***	-.41***	-.51***
17.H Age	-.09	-.08	-.03	.02	.06	.09	.06	-.04	.07	.06	-.09	.03
18.W Age	-.09	-.08	-.06	.02	.07	.07	.08	-.07	.03	.02	-.08	-.01
19.H Education	.02	.04	-.07	.09	.03	-.04	.10	-.07	-.08	.05	.05	-.09
20.W Education	.02	.01	-.06	.08	.04	-.09	.09	-.09	.03	.08	.02	-.05
21.Household Income	.10	.09	.06	.06	.07	.07	.10	-.06	-.06	.07	-.09	-.09
22.H Race	.03	.02	-.03	.01	-.08	-.05	.06	-.08	.04	.00	.02	-.05
23.W Race	.03	.04	-.06	.02	-.09	.076	.08	-.07	.02	.06	.05	-.07
24.Length of Marriage	.04	.04	-.09	.01	-.04	.09	.10	-.09	-.01	.08	.04	-.09
25. # of Children	-.01	.03	-.07	.09	.05	.10	.09	-.07	-.09	.06	-.01	-.10
<i>M</i>	6.59	6.32	107.09	31.40	108.98	31.28	58.87	47.61	51.27	58.45	51.34	51.57
<i>S.D.</i>	9.54	9.18	28.84	9.94	31.26	11.51	12.69	26.19	28.05	12.73	28.40	26.08

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

	13	14	15	16	17	18	19	20	21	22	23	24	25
13.WUplifts Intensity	1.0												
14.WUplifts Frequency	.88***	1.0											
15.HUplifts Intensity	.65***	.60***	1.0										
16.HUplifts Frequency	.55***	.54***	.70***	1.0									
17.H Age	.17*	.18*	.22**	.24**	1.0								
18.W Age	.19*	.20**	.19*	.25**	.08	1.0							
19.H Education	.12	.17*	.08	.15*	.04	.42***	1.0						
20.W Education	.30***	.31***	.12	.17*	.08	.37***	.10***	1.0					
21.Household Income	.39***	.45***	.37***	.38***	.35***	.31***	.32***	.32***	1.0				
22.H Race	.06	.09	-.04	-.02	-.11	-.54	.12	.20**	.19*	1.0			
23. Race	.07	.12	-.05	.04	-.10	.18*	.17*	.23**	.13	.81***	1.0		
24.Length of Marriage	.30***	.33***	.29***	.33***	-.05	.73***	.37***	.30***	.33***	.04	.12	1.0	
25. # of Children	.20**	.20**	.25***	.30***	-.08	.37***	.32***	.15*	.22**	.07	.03	.56***	1.0
<i>M</i>	102.64	28.51	101.91	29.69	39.21	38.01	3.74	3.63	\$55,353	N/A	N/A	11.89	3.09
<i>S.D.</i>	24.18	9.78	27.95	14.29	6.89	7.04	1.06	.95	\$18.649	N/A	N/A	5.42	1.65

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

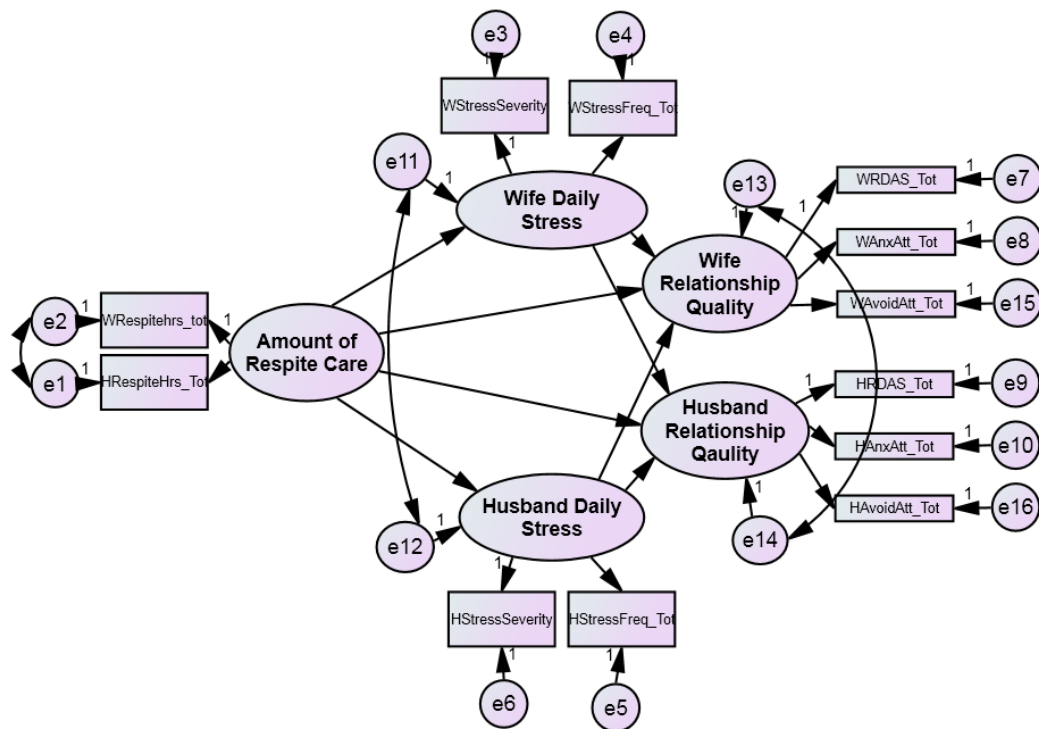


Figure 1. Measurement and actor partner independence structural equation model with amount of respite care predicting husband and wife relationship quality with husband and wife stress as mediating variables.

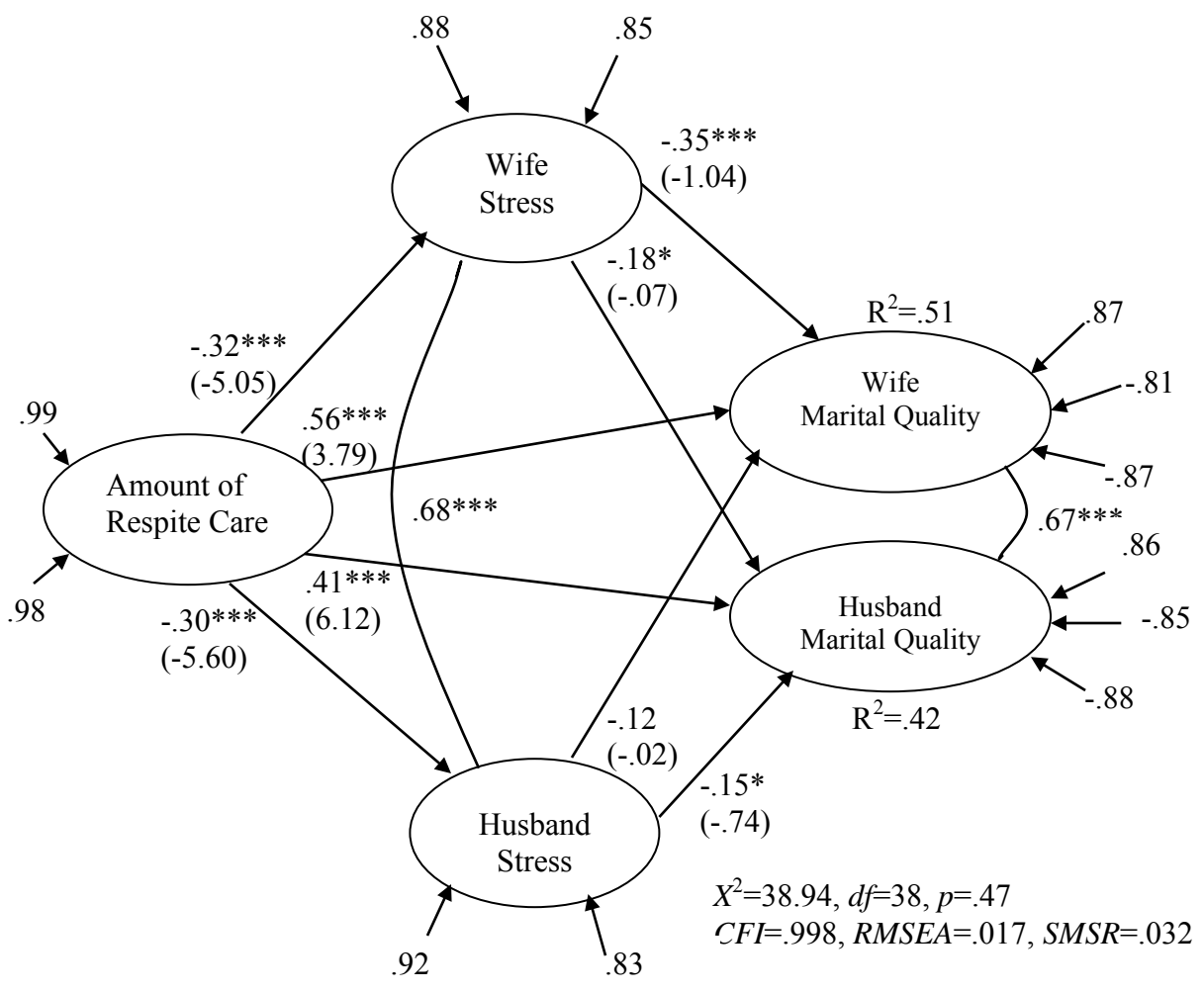


Figure 2. SEM results with standardized betas (unstandardized in parentheses) for amount of respite predicting wife and husband relationship quality with wife and husband stress as potential mediating variables.

Note: Unstandardized Beta Coefficients are in parentheses.

*p<.05, **p<.01, ***p<.001

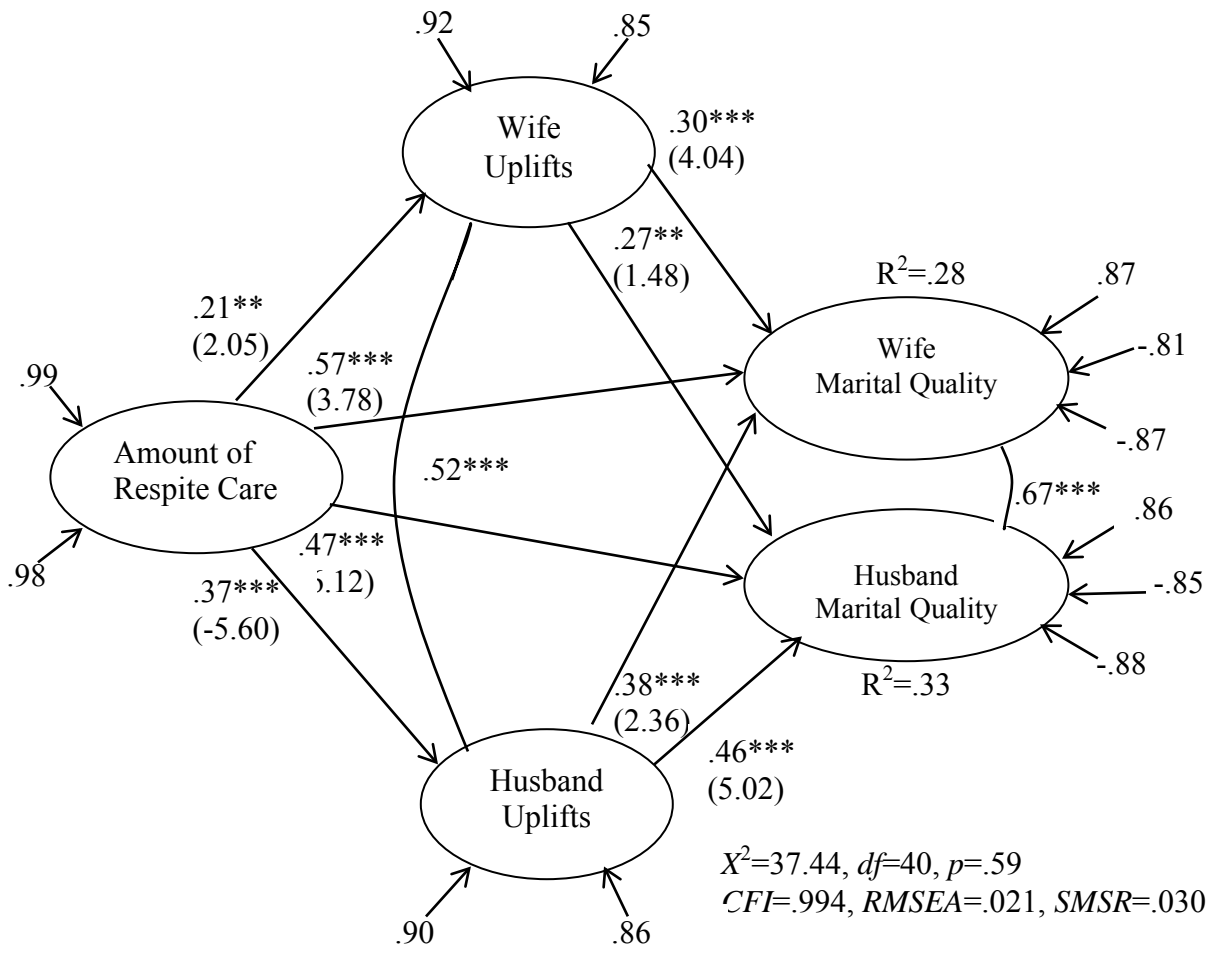


Figure 3. SEM results with standardized betas (unstandardized in parentheses) for amount of respite predicting wife and husband relationship quality with wife and husband uplifts as potential mediating variables.

Note: Unstandardized Beta Coefficients are in parentheses.

*p<.05, **p<.01, ***p<.001

Appendix A - Review of Literature

The following sections review the existing literature regarding Autism Spectrum Disorder (ASD), the definition and prevalence of an ASD, experiences of parenting a child with an ASD, the effects of general stress on marriage, and the relationship between respite care and marital quality of parents with children with an ASD. Having a child with an ASD can contribute to parental stress, which in turn may affect the parents' marital quality. It may be possible that families with children with an ASD who receive respite care will have less stress because they are able to have a break from the demands of providing specialized childcare. Perhaps having less stress will help increase marital quality. If parents are able to have a break from the constant stress of parenting, they may be able to spend time together, which in turn will increase pair bonding, and result in better marital quality.

Characteristics and Definition of Autism Spectrum Disorders

Autism Spectrum Disorders are developmental disabilities defined by atypical development in social skills, communication, and behavior. There are three subcategories included in an ASD: Autism, Asperger Syndrome, and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). Usually characteristics of an ASD are apparent by the age of three. There are two types of an ASD, congenital and regressive. Congenital refers to the child having symptoms of an ASD from birth or shortly thereafter. Regressive refers to the child developing normally and then at a certain age, often around the age of 18 months, they start to regress in their skills such as speech, language, following directions, and cognitive skills (Goin-Kochel & Myers, 2005). Abnormalities in cognitive function, learning, attention, and sensory

processing are found to be fairly common among those with an ASD (Rice, 2006).

To determine an accurate diagnosis of an ASD, professionals look for three main categories of symptoms including deficits in communication, social, and repetitive and idiosyncratic behaviors (Ventola, Kleinman, Pandey, Wilson, Esser, Boorstein, & Fein, 2007). All three subcategories of an ASD differ slightly. To qualify as having Autism, the person must have deficits in all three categories which are communication, social, and repetitive and idiosyncratic behaviors. To qualify as having Asperger's Syndrome the person has deficits in social interaction and repetitive and idiosyncratic behaviors, but they do not have a history of any significant language delay. They may have issues with communicating appropriately, but there is no language delay. To qualify for PDD-NOS, the person must have severe and pervasive deficits in the subcategories, but not to the degree which would qualify the individual to be diagnosed with Autism or Asperger Syndrome.

Communication. In the communication category, there may be a presence of echolalia, delayed speech, syntax issues, volume and tone issues, rate problems, perseveration of sounds and/or words, and trouble with functional communication (American Psychiatric Association, 2000).

Social. Social skills are probably one of the most problematic areas for most people with an ASD. Children with an ASD can have problems with pretend play, imagination, interactive play, hyper focusing on particular topics of interest, interacting with peers, recognizing and understanding social cues, giving consistent eye contact, and behaving appropriately (American Psychiatric Association, 2000).

Repetitive and idiosyncratic behaviors. Self-stimulation is common with people with

an ASD which is often referred to as “stimming.” Children engage in self-stimulatory behavior to help regulate their body and emotional systems. They may be preoccupied with the movement of an object or parts of an object. They may be attached to inanimate objects and want to take them every place they go. They often will spin, flap their hands or arms, walk on their toes, and may exhibit self-injurious behavior (American Psychiatric Association, 2000).

History and Prevalence Rates of ASD

Throughout history there have been historical figures, children with strange behaviors, and fictional characters who seem to have congruency in their personality with characteristics of Autism. Autism seems to have been in existence for centuries, but did not have a name for the unique behaviors and communication of these people until a psychiatrist labeled it. The history of the word Autism began in 1911 with Eugen Bleuler, a Swiss psychiatrist, who first used the term, but applied it to adult schizophrenia. Autism, stemming from the Greek word autos, means self as characterized by extreme withdrawal from being social. In the early 1900s it was referring to the simple disturbance of schizophrenia.

Autism was labeled and described in 1943 by Leo Kanner, a psychiatrist at Johns Hopkins Hospital (Baker, 2010). Kanner believed an ASD was a form of early childhood schizophrenia and later called it early infantile autism. The symptoms of early infantile autism were described as having a profound withdrawal from people, an obsession to preserve sameness, a skillful relation to objects, the retention of an intelligent and pensive outer appearance, and either a complete lack of language or the kind of language that does not seem intended to serve the purpose of interpersonal communication (Kanner, 1943). A physician in Vienna, Hans Asperger, without knowing of Kanner’s publication on Autism, labeled the

description of the social problems children were experiencing as Autistic Psychopathy, which is now known as Asperger's Syndrome (Asperger, 1991/1944; see also Frith, 1991) Later, in the 1950s and 1960s, Dr. Bruno Bettelheim, who directed the Chicago-based Orthogenic School for children with emotional problems, believed that children developed Autism due to unstimulating environments during the first few years of their lives when language and motor skills develop. He reasoned that the mothers of such children were cold, uncaring, distant, and disconnected. From his descriptions the term "refrigerator mother" was born. Bettelheim hindered the study of Autism for years because his theory of "refrigerator mothers" instigated a stigma, which today is one of the myths about an ASD that some people continue to believe (Baker, 2010). For many parents, the only option for treatment of their child with an ASD was psychoanalysis, which was not very successful.

A turning point in views of autism came in 1967 when theories such as the "refrigerator mother" theory were challenged by a mother with a child with an ASD. Clara Park challenged the psychogenic theory in her book, *The Siege*, which described her experiences with her child with an ASD and challenged the medical world. Later, a psychologist and parent of a child with an ASD, Bernard Rimland, founded along with other parents, the National Society for Autistic Children which is currently called The Autism Society of America. The idea was to encourage proper treatment for individuals with an ASD and promote behavioral interventions which were very intense in their focus. Later, the National Society for Autistic Children/Autism Society of America became the authority on an ASD, and the methods they developed became the gold-standard of practice and treatment of children with an ASD (Baker, 2010).

The knowledge and research in the 21st century has continued and will result in better

services and treatments for children with an ASD. With ongoing research and no commonly agreed upon standard of treatment, parenting a child with an ASD can be very difficult and stressful. The parents, probably not knowing what to do when their child is diagnosed and not knowing what treatments to pursue, quickly become overwhelmed and feel burdened.

Parenting a Child with an ASD

Parents with children with an ASD seem to carry many burdens due to their child's disability. These burdens including finding adequate health care for their child and struggling with how to deal with the behaviors of their child.

Health care. Liptak, Stuart, and Auinger (2006) determined that children with an ASD usually incur annual medical expenses on average of \$6,132 compared to \$860 for children who had an intellectual disability, depression, and other children. The economic status and race of the families had no significant effect on the medical expenses. In their methods, Liptak, et al. used national surveys including the Medical Expenditure Panel Survey (MEPS), the National Ambulatory Care Survey (NAMCS), and the National Hospital Ambulatory Care Survey (NHAMCS). These surveys were designed to observe the use and costs of medical care for children and adults. It was shown that 98% of children with an ASD required a special school program such as a special education program. Children with an ASD had more doctor visits, more medications prescribed, spent more time with the physician on average compared to children with intellectual disabilities. Having an ASD is correlated with increased medical illnesses among family members of children with an ASD.

Heidgerken, Geffken, Modi, and Frakey (2005) surveyed primary health care providers' knowledge and practices and compared them to professionals with the Center for Autism and

Related Disabilities (CARD) surveys. The research determined that primary health care providers' beliefs about an ASD were based on outdated criteria. The CARD professionals' information was far more up-to-date. Primary health care providers and specialists were unlikely to refer children with an ASD to special education placement at school due to their beliefs they were less likely to endorse special education services and needs (Heidgerken, et al., 2005). The implications of these findings may mean that some health care providers rely on outdated information, and their beliefs remain unchanged because they may not study current trends regarding an ASD. Volkmar, State, and Klin (2009) discussed the need of using varied and consistent criteria. They made the point that with continuous research and findings there needs to be updated criteria for diagnosing an ASD (Volkmar, et al., 2009). If criterion and beliefs vary significantly, then it is difficult for parents to know what to believe and what to do for their child, and this dilemma leads to more stress in their lives.

Challenging Behaviors. Children with an ASD generally have problematic behaviors and more intense behaviors that can be hard for parents to cope with (Brobst, Clopton, & Hendrick, 2009). Hoffman, Sweeney, Hodge, Lopez-Wagner, and Looney (2009) found that more severe behavioral problems in a child were highly correlated with more extreme levels of stress in the parents. Higgins, Bailey, and Pearce (2005) found that parents reported major concerns about their child's aggression and behavior in public. Behaviors can take a toll on parents and may affect how they parent.

Stress on Families

Having typically-developing children can be stressful at times for parents, but having children with disabilities results in increased parental stress. According to Randall and Parker

(1999), having children with developmental disabilities and/or children with an ASD spectrum disorder may increase stress for the whole family. Families with children with an ASD tend to experience higher levels of stress compared to the general population and parents of children with other developmental disabilities (McKinney & Peterson, 1987; Weiss 2002). Due to the increase of stress in families with children with an ASD, there is a crucial need for these families to have more support. Stress is hard on physical health and mental health. If these families have resources to help relieve stress, then these families have a higher chance of staying healthy and functional. A majority of the stress on the family is caused by the caregiving of the children with an ASD. According to Tehee, Honan, & Hevey (2008), mothers consistently scored higher than fathers on stress measures. The researchers hypothesized that this was because mothers tend to do more of the care giving for the children than do fathers.

Kersh, Hedvat, Hauser-Cram, & Warfield (2006) found that it is important to maintain the parents' well-being to keep a positive family climate. Stress typically affects the well-being of individuals and increases their risk for depression, and parenting stress affects the well-being of both mothers and fathers. Stress has been negatively linked to marital quality of the parents. Parents who have good marital quality usually have more positive outcomes with their children and their children's behavior is decreased (Vandewater & Lansford, 1998). Marital conflict has been linked to children's maladjustment, conduct disorders, anxiety, and aggression (Morrison & Coiro, 1999). Marital conflict that is directly related to the child increases a child's problematic behavior drastically (Snyder, Klein, Gdowski, Faulstich, & LaCombe, 1988). Even when marital conflict is more covert, it is likely to have a spillover effect on the children. Parents who are distracted by tensions within the marriage may not be as involved with their children. If the

parent has a negative relationship with a child then the child tends to act out more and problematic behaviors increase (Harold, Fincham, Osborne, & Conger, 1997). As the quality of the parent child relationship increases, problematic behaviors decrease.

Marital Quality and Parenting Children with Disabilities

Lee, Harrington, Louie, and Newschaffer (2008) examined the quality of life of families that have children with a disability, including children with an ASD. Their study found that families with children with an ASD experience a higher burden of caring than the comparison groups. Children with an ASD were more likely to miss school, repeat grades, and were far less likely to participate in activities. Children with an ASD had major concerns in achievement, self-esteem, stress-coping, learning difficulty, and being bullied. The parents were concerned for their children with an ASD and were more likely to leave a job due to child care issues. The families with children with an ASD were 70% less likely to go to any kind of religious service once a week compared to the other groups. Age of the children with an ASD did not matter when it came to burden of care on the family. At any stage of the family, the families with children with an ASD reported greater stress and burden in comparison to the other groups, which did not have any children with an ASD. They concluded that the families with children with an ASD had a diminished quality of life and higher levels of child caring burden (Lee, et al., 2008).

Hoffman, et al. (2009) compared mothers of children with an ASD and mothers that had children who were typical. These researchers examined the sleep problems in the children and in their parents. In addition they studied parent stress, family processes, and the parent well-being. The mothers with children with an ASD reported higher levels of stress, and the levels reported

were extremely high. The Child Domain subscales indicated that the parent's high levels of stress were related to the children's problematic behaviors (Hoffman, et al., 2009).

Hoffman, Sweeney, Hodge, Nam, and Botts (2008) studied the effects of sleep problems and the mother's stress of children with an ASD. Children with an ASD often have difficulties with sleeping. They found that the mothers' sleep problems were related to the child's sleep problems. The child's sleep problems were correlated with the mother's stress levels, but the sleep patterns of the mother and child did not have any effect on the child's stress levels. The more severe the ASD, the more severe the sleep problems the child would experience. The children with an ASD having sleep problems had a negative effect on family functioning (Hoffman, et al., 2008).

Having a child with an ASD spectrum disorder puts a high level of stress on the family. According to Higgins, et al. (2005), families of children with an ASD had lower marital happiness, family cohesion, and family adaptability compared to families with typical developing children. In comparison to the norm group, families with children with an ASD had a lack of warmth and connection as well as less flexibility. They found that the parents of children with an ASD had a lower level of marital satisfaction compared to those in the norm group. It is possible that by focusing and putting more attention on their child causes the parents to ignore each other and their own relationship needs.

In summary, it is apparent that families with children with an ASD have a greater amount of stress and worries compared to families with typically developing children. The parents worry more about their child's well-being, and the behaviors of the child affect the parents more, which in turn causes higher levels of stress. It may be possible to alleviate some of the stress

these families experience by giving the parents relief from their child with an ASD or from all their children for a brief amount of time.

Respite Care

Thomas, Ellis, McLaurin, Daniels, & Morrissey (2007) studied a community sample of families in North Carolina and discovered access to care and services were related to the child's functioning level, economic status, race, residence, and education. With more severe circumstances such as poverty or living in a more rural area, there was less use of services than those families having a higher education, more money, and living in urban areas. The more difficult the child was, the more likely families were to access services in the community (Thomas, et al., 2007). This study supports the need for respite care for families who have a child diagnosed with an ASD.

Eaton (2008) found that parents who had regular periods of respite care for their child diagnosed with an ASD coped better with their child's burden of care. In Eaton's study the families often didn't know what respite services were available, and there was a very limited availability or no accessible respite care. When respite care is available, there is a strong need that the person who is providing the respite care is supportive and knowledgeable if the care is successful in helping the family cope. When professionals took the time to learn about the individual child they cared for and when they understood the child's non-verbal cues, mothers were more relieved and comfortable with respite care (Eaton, 2008).

In one study, children with developmental disabilities were placed in a center for developmental disabilities for a 30-day period thus giving their parents respite from caring for them. When the child was discharged, parents' distress levels were lower but returned to their

former levels within six months. A comparison group consisted of the child receiving a three to seven day period of respite care. Results seemed to be similar to the results of the 30-day period. This study appeared to show that the family's functional ability improved during the respite care and decreased when the respite care was discontinued. These researchers concluded that maintenance of regular respite care is important for families with a child with developmental disabilities (Mullins, Aniol, Boyd, Page, & Chaney, 2002). If it is maintained, there is a great possibility for the family to function better, have less stress, and possibly the parents would have better marital quality.

According to Cowen and Reed (2002), respite care programs are a critical component in determining parenting stress levels, social support, prevention of child maltreatment, and increased healthy family functioning. The sample of their study consisted of 148 self-referred families and their 265 children with developmental disabilities who were receiving respite care services from agencies in rural areas. Eighty-seven parents completed pre- and post-tests which included the Parenting Stress Index questionnaire. Stress scores were significantly lower at post-test than they were at the pre-test. These authors concluded that there is a need to provide more respite care to make a difference in these families (Cowen & Reed, 2002).

Abelson (1999) found that respite care was not sufficient or available for many families. Reports indicated having respite care available for these families with a disabled child may result in savings to taxpayers due to fewer children in group homes or state hospitals (1999). Respite care may prevent children entering institutions because parents are better able to cope and care for their children.

Reasons for respite care. Chan and Sigafos (2000) explained that families seek respite

care when their children have more severe disabilities, but it is more difficult to secure respite care when children present challenging behaviors and communication difficulties as is the case for children with an ASD. Parents use respite care to help with the level of family stress, access to support systems, family size, and in some cases marital status. The more problematic behaviors present the greater was the need for respite care (Chan & Sigafoos, 2000). Chan and Sigafoos (2001) stated that respite care can alleviate some stress, especially parental stress. Short-term respite care is possibly associated with decrease of parental stress in the families who use it. Long-term effects are unknown due to the lack of research, limitations, and small studies (Chan & Sigafoos, 2001).

Possible solutions for providing respite care. Openden, Symon, Koegel, and Koegel (2006) developed a process to provide more respite care. They recruited college students to do respite care, who in turn, could have the experience and money it offered. The families were able to have support and a break from the stress of caring for their child with an ASD and severe disabilities. These authors emphasized that this is a simple system to set up with students at a local university or community college (Openden, et al., 2006).

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Appendix B - Measures

Demographic Questions

1. What is your current relationship status?

- My current spouse and I are the parents of our child(ren) with Autism Spectrum Disorders.
- I am divorced from the other parent of our child(ren) with Autism Spectrum Disorders, and am living with our child(ren) with Autism Spectrum Disorders.
- *I am divorced from the other parent of our child(ren) with Autism Spectrum Disorders, have remarried, and am NOT living with our child(ren) with Autism Spectrum Disorders.
- *I am divorced, separated, or widowed from the other parent of our child(ren) with Autism Spectrum disorders and have NOT remarried.
- *I am single (never married).

* If this applies to you, please do not continue since the study requires married parents who are living with a child with Autism Spectrum Disorder.

2. How many years have you been married to your current spouse? _____

3. What is your current age in years? _____

4. What is your ethnicity and race?

- Hispanic or Latino
- NOT Hispanic or Latino Race
- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Other

5. What state in the United States do you live in? _____

6. How many hours per week do you work for employment? (If not employed, put 0)

7. What is the highest level of education you have obtained?

- Less than high school education
- High School graduate
- Associate degree or completed some college
- Bachelor's degree
- Master's degree
- Doctorate or Profession degree (e.g., M.D., J.D.)

Respite Care Questionnaire

11. Respite care is short-term care given to your child with an Autism spectrum Disorder by people other than You or your spouse. The respite care may occur in or away from your home and may include caregiving activities such as babysitting, child with ASD spending time with relative including siblings, or a hired worker caring for your child at home or taking your child out for activities or events.

Please indicate below who, if anyone, provides respite care for your child with ASD, the amount of time (in hours and minutes) of respite care in a typical week during the school year, and your satisfaction with this care. **IF YOU DO NOT RECEIVE ANY RESPITE CARE, please continue with the questionnaire and put 0 in hours for respite care.**

	Provides Respite Care?		Amount of WEEKLY time in respite care? (in typical week Sun-Sat during school year) Hours Minutes	Satisfaction with this Respite Care			
	Yes	No		Very Dissatisfied	Dissatisfied	Neutral	Satisfied
Child 1-Grandparent/s				0 0	0	0	0
Child 1-Extended Family Member				0 0	0	0	0
Child 1-Babysitter				0 0	0	0	0
Child 1-Community Agency				0 0	0	0	0
Child1- Other? _____				0 0	0	0	0

12-13. If you have an additional child (children) with an Autism Spectrum Disorder, please complete the question below for your second child. **IF NOT, please skip to Question #16.**

	Provides Respite Care?		Amount of WEEKLY time in respite care? (in typical week Sun-Sat during school year) Hours Minutes	Satisfaction with this Respite Care			
	Yes	No		Very Dissatisfied	Dissatisfied	Neutral	Satisfied
Child 1-Grandparent/s				0	0	0	0

				<input type="radio"/>				
Child 1-Extended Family Member				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child 1-Babysitter				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child 1-Community Agency				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child1- Other? _____				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14-15. If you have an additional child (children) with an Autism Spectrum Disorder, please complete the question below for your third child. IF NOT, please skip to Question #16.

	Provides Respite Care?		Amount of WEEKLY time in respite care? (in typical week Sun-Sat during school year) Hours Minutes	Satisfaction with this Respite Care			
	Yes	No		Very Dissatisfied	Dissatisfied	Neutral	Satisfied
Child 1-Grandparent/s				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child 1-Extended Family Member				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child 1-Babysitter				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child 1-Community Agency				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child1- Other? _____				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. How do you usually spend your time while YOUR CHILD (CHILDREN) RECEIVES RESPITE CARE? If you do not receive respite care, put Not Applicable.

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17. How much time (in hours and minutes) do you usually spend with your spouse in a typical week during the time WHEN YOUR CHILD (children) RECEIVES RESPITE CARE? _____ hours _____ minutes.

18. How much time (in hours and minutes) do you usually spend with your spouse in a typical week WHEN YOUR CHILD (children) IS NOT RECEIVING RESPITE CARE? _____ hours _____ minutes.

Experiences in Close Relationships Questionnaire

► **Instructions:** Read each statement and decide how much you agree or disagree with it.

	Strongly Disagree					Strongly Agree	
1. I prefer not to show a partner how I feel deep down.	1	2	3	4	5	6	7
2. I often worry that my partner will not want to stay with me.	1	2	3	4	5	6	7
3. I feel comfortable sharing my private thoughts and feelings with my partner.	1	2	3	4	5	6	7
4. I'm afraid that I will lose my partner's love.	1	2	3	4	5	6	7
5. I find it difficult to allow myself to depend on romantic partners.	1	2	3	4	5	6	7
6. I often worry that my partner doesn't really love me.	1	2	3	4	5	6	7
7. I am very comfortable being close to my partner.	1	2	3	4	5	6	7
8. I worry that my partner won't care about me as much as I care about him/her.	1	2	3	4	5	6	7
9. I don't feel comfortable opening up to romantic partners.	1	2	3	4	5	6	7
10. I often wish that my partner's feelings for me were as strong as my feelings for him/her.	1	2	3	4	5	6	7
11. I prefer not to be too close to romantic partners.	1	2	3	4	5	6	7
12. I worry a lot about my relationship with my partner.	1	2	3	4	5	6	7
13. I get uncomfortable when my partner wants to be close.	1	2	3	4	5	6	7
14. When my partner is out of sight, I worry that he or she might become interested in someone else.	1	2	3	4	5	6	7
15. I find it relatively easy to get close to my partner.	1	2	3	4	5	6	7
16. When I show my feelings to my partner, I am afraid he/she will not feel the same about me.	1	2	3	4	5	6	7
17. It's not difficult for me to get close to my partner.	1	2	3	4	5	6	7
18. I rarely worry about my partner leaving me.	1	2	3	4	5	6	7
19. I usually discuss my problems and concerns with my partner.	1	2	3	4	5	6	7
20. My romantic partner makes me doubt myself.	1	2	3	4	5	6	7
21. It helps to turn to my partner in times of need.	1	2	3	4	5	6	7
22. I do not often worry about being abandoned.	1	2	3	4	5	6	7
23. I tell my partner just about everything.	1	2	3	4	5	6	7
24. I find that my partner doesn't want to get as close as I would like.	1	2	3	4	5	6	7
25. I talk things over with my partner.	1	2	3	4	5	6	7
26. Sometimes romantic partners change their feelings about me for no apparent reason.	1	2	3	4	5	6	7

	Strongly Disagree					Strongly Agree	
	1	2	3	4	5	6	7
27. I am nervous when my partner gets too close to me.	1	2	3	4	5	6	7
28. My desire to be very close sometimes scares people away.	1	2	3	4	5	6	7
29. I feel comfortable depending on my partner.	1	2	3	4	5	6	7
30. I'm afraid that once my partner knows something personal about me, he or she won't like who I really am.	1	2	3	4	5	6	7
31. I find it easy to depend on my partner.	1	2	3	4	5	6	7
32. It makes me mad that I don't get the affection and support I need from my partner.	1	2	3	4	5	6	7
33. It's easy for me to be affectionate with my partner.	1	2	3	4	5	6	7
34. I worry that I won't measure up to other people	1	2	3	4	5	6	7
35. My partner really understands me and my needs.	1	2	3	4	5	6	7
36. My partner only seems to notice me when I'm angry.	1	2	3	4	5	6	7

Hassles and Uplifts Scale

- **Instructions:** Hassles are things that annoy or bother you. They can make you upset or angry. Circle the number on the left that represents how much of a hassle that item has been for you during the last 6 months. Uplifts are things that make you feel good. They can make you glad or satisfied. Circle the number on the right that represents how much of an uplift that item has been for you during the last 6 months. Each item should have a number circled on the left side and a number circled on the right side.

HASSLES					UPLIFTS			
How much of a hassle was this for you?					How much of an uplift was this for you?			
0	1	2	3		0	1	2	3
0	1	2	3	1. Your children	0	1	2	3
0	1	2	5	2. Your parents or parents in law	0	1	2	3
0	1	2	3	3. Your spouse	0	1	2	3
0	1	2	3	4. Other relatives	0	1	2	3
0	1	2	3	5. Time spent with family	0	1	2	3
0	1	2	3	6. Health or well being of a family member	0	1	2	3
0	1	2	3	7. Sex	0	1	2	3
0	1	2	3	8. Intimacy	0	1	2	3
0	1	2	3	9. Family related obligations	0	1	2	3
0	1	2	3	10. Your friends	0	1	2	3
0	1	2	3	11. Co-workers	0	1	2	3
0	1	2	3	12. Clients, customers, patients, etc.	0	1	2	3
0	1	2	3	13. Supervisor or employer	0	1	2	3
0	1	2	3	14. Nature of your work	0	1	2	3
0	1	2	3	15. Your work load	0	1	2	3
0	1	2	3	16. Your job security	0	1	2	3
0	1	2	3	17. Meeting deadlines or goals on the job	0	1	2	3
0	1	2	3	18. Enough money for necessities such as food, clothing, housing, health care, taxes, insurance.	0	1	2	3
0	1	2	3	19. Enough money for education	0	1	2	3
0	1	2	3	20. Enough money for emergencies	0	1	2	3
0	1	2	3	21. Enough money for extras such as entertainment, recreation, vacations, etc.	0	1	2	3
0	1	2	3	22. Financial care for someone who doesn't live with you	0	1	2	3
0	1	2	3	23. Investments	0	1	2	3
0	1	2	3	24. Your smoking	0	1	2	3
0	1	2	3	25. Your drinking	0	1	2	3
0	1	2	3	26. Effects of drugs and medications	0	1	2	3
0	1	2	3	27. Your physical experience	0	1	2	3
0	1	2	3	28. Time alone	0	1	2	3

HASSLES					UPLIFTS			
How much of a hassle was this for you?					How much of an uplift was this for you?			
0	1	2	3	29.Exercise (s)	0	1	2	3
0	1	2	3	30.Your medical care	0	1	2	3
0	1	2	3	31.Your health	0	1	2	3
0	1	2	3	32.Your physical abilities	0	1	2	3
0	1	2	3	33.The weather	0	1	2	3
0	1	2	3	34.News events	0	1	2	3
0	1	2	3	35.Your environment (quality of air, noise level, greenery, etc.)	0	1	2	3
0	1	2	3	36.Political or social issues	0	1	2	3
0	1	2	3	37.Your neighborhood	0	1	2	3
0	1	2	3	38.Conserving (gas, electricity, water, gasoline, etc.)	0	1	2	3
0	1	2	3	39.Pets	0	1	2	3
0	1	2	3	40.Cooking	0	1	2	3
0	1	2	3	41.Housework	0	1	2	3
0	1	2	3	42.Home repairs	0	1	2	3
0	1	2	3	43.Yard work	0	1	2	3
0	1	2	3	44.Car maintenance	0	1	2	3
0	1	2	3	45.Taking care of paperwork (paying bills, filling out forms, etc.)	0	1	2	3
0	1	2	3	46.Home entertainment (TV, music, reading, etc.)	0	1	2	3
0	1	2	3	47.Amount of free time	0	1	2	3
0	1	2	3	48.Recreation and entertainment outside the home (movies, sports, eating out walking, etc.)	0	1	2	3
0	1	2	3	49.Eating (at home)	0	1	2	3
0	1	2	3	50.Church or community organizations	0	1	2	3
0	1	2	3	51.Legal matters	0	1	2	3
0	1	2	3	52.Being organized	0	1	2	3
0	1	2	3	53.Social commitments	0	1	2	3

Appendix C - Consent to be a Research Subject

Respite Care and Marital Quality Project

Introduction

This research study is being conducted by Amber Harper, a master's student at Brigham Young University and Autism Specialist at Giant Steps, Wasatch Mental to determine how the amount of respite care affects the quality of a marriage in parents who have a child diagnosed with an Autism Spectrum Disorder. You and your spouse were invited to participate because you are married and have a child with an Autism Spectrum Disorder.

Procedures

If you agree to participate in this research study, the following will occur:

- You and your spouse will receive a questionnaire by your choice of mail, e-mail, or online internet link.
- The questionnaire will include questions regarding your age, length of marriage, household income, family size, questions about amount of respite care you receive, questions about stress in your life, and questions about your marriage.
- It will take 45 minute to one hour to complete the questions and you may complete these in your home. You will do this independently of each other and will be asked not to share your answers with each other.
- Each of you will return these questionnaires using the method you received them.
- Total time commitment will be 45 minutes to one hour.

Risks/Discomforts

There are minimal risks for participation in this study. However, you may feel some discomfort when answering questions about individual stress or your marital relationship. Answering the questions independently of each other will help minimize this discomfort.

Benefits

There will be no direct benefits to you. However, it is hoped that through your participation researchers will learn more about how to help parents who are caring for a child with an Autism Spectrum Disorder, specifically whether receiving respite care helps guard the parents' marriage.

Confidentiality

The research data will be kept in a password protected computer, and only the researchers will have access to the data. At the conclusion of the study, all identifying information will be removed and the data will be kept in the researcher's locked office.

Compensation

You will receive a 30 dollar gift card when both husband and wife questionnaires are completed

and returned.

Participation

Participation in this research study is voluntary. You have the right to withdraw at any time or refuse to participate.

Questions about the Research

If you have questions regarding this study, you may contact Amber Harper at (801) 362-7102 or at amberharper@gmail.com or Tina Dyches, Ph.D. at (801) 422-5045.

Questions about your Rights as Research Participants

If you have questions regarding your rights as a research participant, you may contact IRB Administrator, (801) 422-1461, A-285 ASB Campus Drive, Brigham Young University, Provo, UT 84602 or irb.byu.edu.

I have read, understood, and received a copy of the above consent and desire of my own free will to participate in this study.

Husband's Signature: _____ Date: _____

Wife's Signature: _____ Date: _____