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Respite Care and Marital Quality in Parents of Children with Down Syndrome

Michelle Norton

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

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ABSTRACT

Respite Care and Marital Quality in Parents of Children with Down Syndrome

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Parents of a child with a disability are at greater risk than other couples for having higher stress, adjustment difficulties, and lower marital quality. Respite care has been shown to reduce stress in parents of children with disabilities. This study focused on parents who have a child with Down syndrome and their reported marital quality and respite care received. One hundred and twelve couples, each consisting of a mother and a father who lived with their child with Down syndrome, completed questionnaires including the Revised Dyadic Adjustment Scale, Experience in Close Relationships Questionnaire, Daily Hassles and Uplifts Scale, and a respite questionnaire. Results were mixed. Respite care did not predict marital quality for either wives or husbands. However, respite hours was related to wife stress, which was in turn related to wife marital quality. Respite hours was also related to husband stress, which was related to husband marital quality. In addition, wife uplifts was directly related to wife marital quality and to husband marital quality. Husband uplifts was related to husband marital quality. While not directly predicting marital quality, respite care was indirectly related to increases in marital quality through stress. Therefore, it is important that respite care be accessible and provided to parents who have a child with Down syndrome. Recommendations for policy makers and researchers are offered.

Keywords: respite care, marital quality, marital satisfaction, stress variables, Down syndrome

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DESCRIPTION OF THESIS STRUCTURE

This thesis, *Respite Care and Marital Quality in Parents of Children with Down Syndrome*, is written in a hybrid format, which combines traditional thesis requirements with a university-approved journal-ready format. The thesis conforms to the length and style requirements for submission to a targeted journal in the field of disability/family issues.

The first part of this thesis includes the journal-ready article and its accompanying reference list. The more traditional review of literature section is included in Appendix A, with its accompanying reference list. Appendix B contains the recruitment materials used in the study, Appendix C contains the consent to be a research participant, and Appendix D contains the measures.

Introduction

Down syndrome is among the most prevalent chromosomal disabilities, with one out of every 691 babies being born with the condition each year (Centers for Disease Control and Prevention, 2012). The cause of Down syndrome has been linked to a genetic adaptation of chromosome 21 (Sherman, Allen, Bean, & Freeman, 2007) that results in deficits in both intellectual and adaptive functioning (Naess, Lyster, Hulme, Melby-Lervag, 2011; Penna & D'Andrea-Penna, 2009). In addition to those disadvantages, individuals with Down syndrome have a heightened risk for developing behavioral problems (Eisenhower, Baker, & Blacher, 2005) and for experiencing health problems such as obesity (Chad, Jobling, & Frail, 1990; Prasher, 1995), heart defects (Vida et al., 2005), ocular (Stephen, Dickson, Kindley, Scott, & Charleton, 2007) and auditory disorders (Shott, Joseph, & Heithaus, 2001).

Children with Down syndrome are seen as having a few advantages over other disabilities, such as greater social competence, responsiveness to people, ability to use language to communicate, and having a caring and gentle personality (Hodapp, Ly, Fidler, & Ricci, 2001). However, when compared to typically developing children, this "Down syndrome advantage" diminishes. Dykens (2007) demonstrated that children with Down syndrome display more behavioral problems such as stubbornness, oppositionality, and speech problems, when compared to children who are developing typically.

Having a child with a disability can greatly impact family functioning. There has been some debate about how a family adapts and copes with having a child with Down syndrome as compared to other disabilities. Compared to families who do not have a child with a disability, families with Down syndrome report higher stress levels, adjustment difficulties, and poor coping abilities (Hodapp & Urbano, 2007). Mothers who have a child with Down syndrome are

also far more likely to report symptoms of depression and poor well being as compared to mothers who do not have a child with a disability (Bailey, Golden, Roberts, & Ford, 2007).

While parenting in general can be stressful and demanding, parenting a child with a disability such as Down syndrome presents greater challenges. Families must often adapt familial activities and outings to meet the needs and ability of their child. Likewise, these activities are often restricted because of maladaptive behavior that the child may display. Adding to this stress, parents are also concerned about the negative impact the child might have on other siblings in the family: the child with a disability often takes more of their attention and restricts the social life of the siblings as they are often needed to help care for the child (Povee, Roberts, Bourke, & Leonard, 2012).

These familial and other stressors place a burden on the marital relationship. The distress that families of children with developmental disabilities experience has been shown to be negatively related to the marital quality of the parents (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). In a meta-analysis of 13 different studies looking at marital satisfaction and divorce in families who have a child with a disability and without a disability, the divorce rate of parents who have a child with a disability was, on average, 5.97% higher than parents who do not have a child with a disability. However, the effect size between the level of marital stress and having a child with a disability was relatively small. The combined group size in this meta-analysis totaled 48,254 comparison participants with 6,270 participants in the disability group (Risdal & Singer, 2004). Other research indicates marital quality is directly linked to parents' well being and depressive symptoms, especially in mothers. Mothers of children with disabilities report lower marital quality, in addition to depressive symptoms and well being, when compared to mothers who do not have a child with a disability (Norlin & Broberg, 2013).

While research indicates that individual stressors negatively influence marital quality and well being, there are a limited number of studies that address the influence of partner effects on marital quality. Most studies investigate both husbands and wives independently to determine how the stress of having a child with a disability impacts their marital quality (Kersh et al., 2006). In addition, a large portion of the research only addresses the impact having a child with a disability has on wives' marital quality and psychological functioning (Bailey et al., 2007; Norlin & Broberg, 2013), but does not address husband marital quality and functioning. The few studies that address husband stress while raising a child with a disability (Keller & Honig, 2004) do not investigate the impact their stressors have on wife marital quality.

In order to address these deficits, an Actor-Partner Interdependence Model (APIM) has been used increasingly in the social sciences (Cook & Kenny, 2005). This model allows researchers to investigate the characteristics of the individuals who provide the scores, but also the characteristics and impact on the individual's partner, also known as partner effects. APIM is designed to measure the interdependence within interpersonal relationships. A consequence of having an interdependent relationship is that the perceptions and observations of two individuals are linked or correlated, such that the knowledge one person provides may provide information about the other person's functioning. Using this model, researchers are able to study the relationships interdependently and gain a better aspect of marital functionality (Cook & Kenny, 2005).

As has been discussed, current research shows that parenting a child with a disability can impact individual, marital, and familial functionality (Bailey et al., 2007; Hodapp & Urbano, 2007; Kersh et al., 2006). With the added stress that having a child with a disability places on marital relationships, it is vital to provide resources to those families. As will be discussed,

respite care is one resource that has been shown to positively affect families who have a child with a disability.

Respite Care as a Resource

Respite care has been found to be a positive tool in helping families cope with the challenges they face (Robertson et al., 2011). Respite care involves giving the family, specifically the parents, a limited break from the responsibilities in caring for their child with disabilities. This could include having someone come into the home to care for the child or taking the child out of the home to provide the family with a short break. Conducting a meta-analysis, Robertson et al. (2011) concluded that respite care can have a beneficial impact on the parents' well being. Specific benefits include reduced stress, rest and relaxation, a sense of relief, freedom to do something for themselves, alleviating exhaustion, and promoting a sense of renewal.

Respite care has also been shown to increase the ability of the family and the child to function in day-to-day life (Mullins, Aniol, Boyd, Page, & Chaney, 2002). Brief three to seven day respite care has been shown to have positive effects on familial functioning as well as on the ability of the child to function. In addition, parental stress and psychological distress levels decreased significantly (Mullins et al., 2002). Equally, respite care can be a great tool in encouraging parents who have a child with a disability to include health activities, prioritization of oneself, and time management in their schedule (Bourke-Taylor, Pallant, Law, & Howie, 2012).

Respite care can also have positive benefits on the parents' perceived marital quality. A recent study found that respite care is associated with improved marital quality of couples who have a child with Autism Spectrum Disorder (ASD; Harper, Dyches, Harper, Roper, & South,

2013). Social support such as respite care has been found to be a predictor of marital quality in parents who have a child with a developmental disability (Kersh et al., 2006). Although much has been investigated regarding the familial advantage to having a child with Down syndrome as opposed to another disability, there is a limited amount of research examining if respite care benefits families who have children with Down syndrome. This study examines the relationship between respite care and the marital quality of parents who have a child with Down syndrome, with daily stress and uplifts as potential mediating variables.

Statement of the Problem

While some research has been conducted to examine how respite care affects families raising a child with a developmental disability, no published studies have been found focusing specifically on families with a child with Down syndrome and how respite care is related to the marital quality of the parents. Research has shown that having a child with developmental disabilities places extra stresses on the marital quality of the parents and that respite care may be a positive tool in helping parents relieve that stress. In addition, no studies have been conducted to examine how resources in the form of daily uplifts are related to the quality of marriage.

Statement of Purpose

The purpose of this study is to: (a) examine the relationship between respite care and marital quality of married couples who have a child with Down syndrome, while examining wife and husband stressors as potential mediating variables, and (b) assess husband and wife daily uplifts as potential mediating variables.

Research Questions

This study will address the following research questions:

1. Is there a relationship between the amount of respite care received and marital

quality of parents who have a child with Down syndrome?

2. Does perceived stress and uplifts of the mother and the father mediate the relationship between respite care and marital quality?

Hypotheses

The hypothesized relationships are shown in Figures 1 and 2.

1. Amount of respite care will be positively correlated with perceived marital quality for both husbands and wives.
2. Amount of respite care will be positively correlated with daily uplifts for both husbands and wives.
3. Amount of respite care will be negatively correlated with daily stressors for both husbands and wives.
4. Daily stressors will be negatively correlated with marital quality for both husbands and wives.
5. Daily uplifts will be positively correlated with marital quality for both husbands and wives.
6. Partner effects from wife daily stress will be negatively related to husband marital quality and husband daily stress will be negatively related to wife marital quality, even when controlling for the relevant actor effects.
7. Partner effects from wife daily uplifts will be positively related to husband marital quality and husband daily uplifts will be positively related to wife marital quality, even when controlling for the relevant actor effects.
8. The relationship between respite care and marital quality will be significantly mediated by daily stresses and uplifts.

Method

The purpose of this study was to examine the relationship between respite care and marital quality with stress and uplifts as potential mediating variables. This section reviews participants and settings, measures, and data analysis.

Participants and Settings

Contact was made with national organizations including the National Association for Down Syndrome, National Down Syndrome Congress, National Down Syndrome Society, The Arc, and Band of Angels Foundation, as well as local or regional organizations such as the Utah Down Syndrome Foundation and Friday's Kids Respite. These organizations were asked to put a short description of the research in their paper/electronic communications with a link to the survey (See Appendix B). The survey was posted online through Qualtrics. Inclusion criteria included: (a) the parents have a child, (any age), with Down syndrome as classified by a medical diagnosis, and (b) the parents are a heterosexual couple that are married to each other and living together. This criterion was specified in order to better compare the results of this study to the Harper et al. (2013) study, which investigated marital quality and respite care of parents who have a child with ASD. Each partner was instructed to complete the survey on his or her own and each couple was given a \$25 gift card upon both wife and husband completion of the survey. Each participant signed or indicated consent by completing the survey (See Appendix C). The survey remained online until at least 100 couples completed the measures.

Measures

Five different measures were used in this study in order to measure marital quality, daily hassles and uplifts, respite care, and demographic information. This section reviews those measures.

Marital quality. Two scales were used to measure marital quality (see Appendix D). First was the Revised Dyadic Adjustment Scale (RDAS; Busby, Clark, Crane, & Larson, 1995), which contains 14 items split into three subscales: cohesion, consensus, and stability. For the consensus subscale, participants answer the items using a 6-point Likert scale ranging from 0 (*Always Disagree*) to 5 (*Always Agree*). Examples of questions from this subscale include “Please indicate the extent of agreement between you and your partner on religious matters,” and “Please indicate the extent of agreement between you and your partner on conventionality (correct or proper behavior).” The stability subscale contained 4 items ranging on a 6-point Likert scale from 0 (*all the time*) to 5 (*Never*). Examples include, “How often do you discuss or have you considered divorce, separation, or terminating your relationship?” and “How often do you and your partner quarrel?” The cohesion subscale consists of four items answered on 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 have a stimulating exchange of ideas?” and “How often do you and your mate work on a project together?” The sum of the 14 items on the subscales yields scores ranging from 0 to 70. The cut off score of 48 discriminates between non-distressed couples and distressed couples, with lower scores indicating lower perceived marital quality (Busby et al., 1995).

The RDAS demonstrates strong reliability and validity. When developing this measure, Busby et al. (1995) established reliability by dividing the items on the scale in half and giving each half to respondents, with the final split half reliability coefficient being .94. Concurrent validity was established through comparing scores from the Marital Adjustment Test (MAT), which resulted in a coefficient of .68. This coefficient was higher than the correlation between the Original Dyadic Adjustment Scale and the MAT (Locke & Wallace, 1959). Predictive

validity was good with an 86% accuracy rate of predicting membership as either a distressed or a non-distressed couple. In addition, factor analyses were conducted using LISREL (Joreskog & Sorbom, 1989), and loadings on the stated factors ranged from .74 to .97 (Busby et al., 1995).

The second scale that was used to measure marital quality is the Revised Experiences in Close Relationships Questionnaire (RECRQ; Fraley, Waller, & Brennan, 2000). Specifically, this scale measures the degree of attachment in a romantic relationship. It is made up of two subscales, anxiety and avoidance, both containing 18 questions. Husbands and wives answer each item using a 7-point Likert scale, which ranges from 1 (*strongly disagree*) to 7 (*strongly agree*). Items for the anxious attachment subscale include “My romantic partner makes me doubt myself” and “I do not often worry about being abandoned.” The avoidant attachment subscale includes items such as, “I am very comfortable being close to my partner” and “I usually discuss my problems and concerns with my partner.” Total scores from both subscales range from 18 to 126. When developing this measure, Main and Cassidy (1988) found inter-item reliability for the anxious attachment subscale was .93 and .95 for the avoidant attachment subscale. In regards to validity, the anxious attachment scale has been shown to be correlated at .74 with the adult attachment interview, while the avoidant attachment scale correlated at .68 with the avoidance section in the adult attachment interview (Main & Cassidy, 1988).

Daily hassles and uplifts. The Hassles and Uplifts Scale (HUS; Lazarus & Folkman, 1984) uses a Likert scale ranging from 1 (*not at all*) to 4 (*extreme*), to rate how much each of the 53 items is a daily hassle and how much it is a daily uplift. Hassles are defined as things that annoy or bother the person and can possibly make them upset or angry while uplifts are things that make the individual feel good, glad, or satisfied. Each item is rated on how much of a hassle it is and how much of an uplift it is on a daily basis. Examples of items include, “Your

children,” “Family related obligations,” and “Nature of your work.” Ranging from 0-53, the frequency score was calculated by separately summing the number of items that have a score greater than zero for both the hassles and uplifts. An intensity score, ranging from 0 to 212, was also calculated for both the hassles and uplifts by summing the score of each answer to all the items. The hassles frequency score combined with the hassles intensity score was used as a latent variable called stress for each partner in the relationship. The uplifts frequency score combined with uplifts intensity score was used as a latent variable called uplifts for each partner in the relationship.

The HUS demonstrates strong reliability and validity. Touliatos, Perlmutter, and Straus (1990) reported the test/retest reliability to be $r = .79$ for hassles items and $.82$ for the uplift items. In regards to validity, the HUS has been shown to correlate with both illness and distress. DeLongis, Coyne, Dakof, Folkman, and Lazarus (1982) showed that hassles were strongly associated with somatic health. DeLongis, Folkman, and Lazarus (1988) reported a high correlation between subjects who reported being low in both self-esteem and supportive social relationships and psychological and somatic difficulties. In regards to construct validity, Kanner, Coyne, Schaefer, and Lazarus (1981) found a correlation of $.21$ for both men and women between reported life events and hassles frequency.

Respite care. For the purposes of this study, respite care was defined as “planned care for the child with Down syndrome to provide relief to the permanent caregiver.” Respite care was measured using two questions. The first question asked each participant to report how much respite care they receive Monday-Friday, in hours and minutes, within a typical week. The second question addressed how much respite care the individual receives on a typical weekend, Saturday-Sunday. The responses to these questions were summed to create a total amount of

respite care received. If there was more than one child receiving respite care in the family, two steps were taken. First, if the reported hours were the same for each child, the hours for the second child were not counted as additional respite hours. Second, if the additional reported hours for the second child were different from the hours for the first child, then those hours were added to the total sum of respite care received. The total reported hours of both the husband and the wife were summed and were both indicators for the latent variable, amount of respite care.

Demographic information. Each participant was asked to complete a demographic questionnaire including questions about race, ethnicity, employment, salary, education, number of children, annual household income, age, gender, and medical diagnoses of the child/or children. These factors were used as control variables in the analysis of the data.

Data Analysis

The first step in data analysis was to examine descriptive statistics. Means, standard deviations, and correlations between all study variables were calculated. A measurement model for each of the latent variables (respite care, marital quality, hassles and uplifts) was also tested. Data were analyzed using AMOS 17 (IBM Corp, 2012) to perform structural equation modeling. An Actor Partner Independence Model (APIM; Kenny, Kashy, & Cook, 2006) was used to estimate the effects of the amount of respite care on husband and wife relational quality (hypothesis 1; see Figures 1 and 2). The path between amount of respite care and wife/husband daily uplifts (hypothesis 2) as well as daily stress (hypothesis 3) was estimated. The path between both the wife and husbands daily stressors (hypothesis 4) daily uplifts (hypothesis 5) and marital quality was calculated. The partner effects are the influence of each partner's variables on his or her spouse. The partner effects from wife daily stress and husband marital quality were calculated as well as the partner effects from husband daily stress and wife marital

quality (hypothesis 6). The partner effect from wife daily uplifts and husband marital quality as well as husband daily uplifts and wife marital quality were also estimated (hypothesis 7). The indirect path of both wife and husband daily uplifts/stresses was also calculated, with uplifts/stresses as mediating variables between respite care and marital quality (hypothesis 8).

Results

Three hundred and thirty-seven surveys were submitted online; however, only 224 (112 wives and 112 husbands) contained useable responses. The 113 surveys were not included because they were not fully completed, did not have a matching spouse who completed the survey, or had taken the survey multiple times. Therefore, this study consisted of data from 112 married couples who have a child with Down syndrome. The demographics (e.g., age, length of marriage, number of children, income, relationship status, education, race) of these couples appear in Table 1.

Average age for husbands was 39.06 ($SD = 8.53$) and 37.61 ($SD = 8.39$) for wives. Average length of marriage reported was 10.95 ($SD = 7.66$) for both husbands and wives, with an average of 2.65 ($SD = 1.25$) children reported for both husbands and wives. Almost half of the husbands (47.3%) and 50% of the wives had earned at least a Bachelor's degree. The reported race of the participants were predominantly White (husbands = 87.5%; wives = 88.3%). Almost all of the participants were the biological parents of the child with Down syndrome (husbands = 99.1%; wives = 96.4%).

Respite Care

Fifty-seven percent of the families reported receiving respite care. Wives reported mean respite hours of 5.45 per week ($SD = 9.10$) and husbands reported mean respite hours of 5.61 per week ($SD = 10.5$). The correlation between the wives' report of respite hours and the husbands'

report of respite hours was .83 ($p < .001$), indicating that both wives' and husbands' perceptions were extremely similar in reporting respite care hours.

Of the different forms of respite care reported by the couples receiving respite care, 68.3% ($n = 43$) of the care was provided by grandparents, 34.9% ($n = 22$) reported care provided by a babysitter, 22.2% ($n = 14$) reported care provided by extended family, 14.3% ($n = 9$) reported care provided by some other resource such as siblings or tutors, and 12.7% ($n = 8$) reported care provided by an agency. Twenty-two percent ($n = 14$) reported receiving respite care from multiple providers. Of the couples receiving respite care, 87.4% were satisfied or highly satisfied with the respite care received, and 12.6% were neutral or dissatisfied with the respite care. See Table 2 for more information related to the demographic characteristics of the children with Down syndrome ($n = 167$ males, 130 females) and the type of respite care their parents received, if any.

Marital Quality

Overall marital quality statistics are presented in this section. Husbands' and wives' average marital quality scores, as measured by the RDAS, were 62.70 ($SD = 8.63$) and 60.59 ($SD = 9.98$) respectively. As indicated by the RDAS scores, 3.6% of husbands and 9.8% of wives were in the distressed marriage range (cut-off scores below 48; Busby et al., 1995). Mean anxious attachment for wives was 40.22 ($SD = 19.72$) and for husbands was 44.77 ($SD = 22.52$) out of possible 126, with lower numbers indicating less anxious attachment. Mean avoidant attachment was 46.70 ($SD = 25.29$) for wives and 43.07 ($SD = 19.57$) for husbands out of a possible 126, with lower numbers being less avoidant attachment.

Stress and Uplifts

Wives' and husbands' mean severity stress scores were 99.89 ($SD = 24.81$) and 93.25 ($SD = 24.16$), respectively. In terms of the average number of times husbands and wives endorsed items as stressful (stress frequency scores), wives' mean score was 27.76 ($SD = 10.23$), and husbands' mean score was 25.59 ($SD = 11.64$). This indicates that, together, both husbands and wives were endorsing slightly over 50% of the 53 items as stressful. The severity scores were moderate but within average range ($T = 62.2$ for husbands and 63.8 for wives). This means that, on average, husbands exhibited more stress than 62.2% of men in a normed sample and that wives exhibited more stress than 63.8% of women in a normed sample.

In terms of the average number of times husbands and wives endorsed items as uplifts (uplift frequency scores), wives reported a mean of 30.08 ($SD = 10.02$), and husbands reported a mean of 31.53 ($SD = 9.82$) out of 53 items. Husbands' and wives' mean uplifts intensity scores were 109.74 ($SD = 25.74$) and 111.75 ($SD = 27.35$), respectively. The uplift intensity scores were slightly higher for husbands than wives ($T = 60.6$ for husbands and 57.4 for wives), but both were in the normal range. This means that 39.4% of men in a normal population would score higher (have more uplifts) than the husbands in this sample, and 42.6% of women in a normal population would score higher (have more uplifts) than the wives in this sample.

Correlations Between Study Variables

Many variables in this study had significant relationships with other variables. Therefore, only highlights of some of the strongest correlations will be presented in this section, emphasizing respite care and marital quality. See Table 3 for a report of the correlations, means, and standard deviations for each of the measured variables in the study.

Respite care. Significant positive correlations related to respite care existed between several variables such as frequency of uplifts and marital quality (as measured by RDAS scores). For example, the amount of wives' respite care was positively correlated with husbands' uplifts frequency ($r = .15, p < .05$); husbands' respite care was also significantly correlated with their uplifts frequency ($r = .16, p < .05$). The amount of respite care for wives was positively correlated with marital quality ($r = .15, p < .05$), indicating that the more respite care wives received, the greater their perception of marital quality. However, though statistically significant, these correlations were rather small.

The correlation of both wives' and husbands' respite hours were significantly negatively correlated with two variables: stress severity and stress frequency. For example, negative correlations existed between respite hours and severity of stress ($r = -.20, p < .05$ for wives; $r = -.19, p < .05$ for husbands), indicating the fewer respite care hours they received, the more severe the stress they experienced.

Marital quality. Wives and husbands' perceptions of marital quality (as measured by RDAS scores) were positively correlated to frequency and intensity of daily uplifts. Husbands' perception of marital quality was significantly related to both husbands' and wives' reports of uplift intensity ($r = .34, p < .001$ for husbands; $r = .40, p < .001$ for wives) and frequency ($r = .33, p < .001$ for husbands; $r = .27, p < .001$ for wives). Wives' perception of marital quality was significantly related to their own uplifts (intensity $r = .40, p < .001$; frequency $r = .36, p < .001$) and husbands' intensity of daily uplifts ($r = .20, p < .05$).

Significant negative correlations existed between marital quality (as measured by RDAS scores) and husbands' and wives' reports of daily stress. For example, for wives, marital quality was negatively correlated with severity and frequency of stress ($r = -.43, p < .001$; $r = -.37, p < .001$

respectively). For husbands, marital quality was also negatively correlated with severity and frequency of stress ($r = -.46, p < .001$; $r = -.47, p < .001$ respectively).

Measurement and Structural Model Results

Figure 3 shows the factor loadings for each measured variable on their respective latent variables, as well as the standardized and unstandardized Beta coefficients for statistically significant structural paths in the model with husband and wife stress as potential mediators. The overall fit indices for the model with husband and wife stress as potential mediators showed that the hypothesized model was a good fit to the actual data based on Kline's (2010) recommendations. The chi square was insignificant ($X^2 = 39.98, df = 33, p = .22$); the Comparative Fit Index (*CFI*) was well above .95 ($CFI = .990$), the Root Mean Square Error of Approximation (*RMSEA*) was less than .05 ($RMSEA = .04$), and the Standardized Root Mean Square Residual (*SRMR*) was less than .08 ($SRMR = .05$). The overall R^2 was .30 for husbands' marital quality, and .21 for wives' marital quality meaning that the overall model explained 30% of the variance for husbands' marital quality and 21% of the variance for wives' marital quality.

Figure 4 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 model was a good fit to the actual data with a *CFI* of .99, an *RMSEA* of .05 and an *SRMR* of .05. The chi square was insignificant ($X^2 = 40.59, df = 33, p = .17$). The overall R^2 for this second model was .17 for husbands and .14 for wives.

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 marital relationship quality for both husbands and wives. As shown in Figure 3 with stress as the mediating variables, the relationship between the amount of respite care and marital quality for

husbands ($\beta = -.06$) and wives ($\beta = -.13$) was not statistically significant. As can be seen in Figure 4 with uplifts as the mediating variables, there were not statistically significant relationships between the amount of respite care and marital quality for either partner ($\beta = .04$ for husbands; $\beta = .09$ for wives). Therefore, hypothesis 1 was not supported.

Hypothesis 2 results: Amount of respite care and daily uplifts. Hypothesis 2 stated that there would be a significant positive relationship between amount of respite care and daily uplifts. Figure 4 shows that the relationship between the hours of respite care and husbands and wives daily uplifts was not significant ($\beta = .14$; $\beta = .06$ respectively). Therefore, hypothesis 2 was not confirmed for either husbands or wives.

Hypothesis 3 results: Amount of respite care and daily stressors. Hypothesis 3 stated that there would be a significant negative relationship between respite care and daily stressors for husbands and wives. As seen in Figure 3, there was a significant negative relationship between amount of respite care and wife daily stress ($\beta = -.19, p < .05$) and between the amount of respite care and husband daily stress ($\beta = -.20, p < .05$). Unstandardized betas indicated that for every hour of respite care, daily stress decreased by approximately four-tenths of a unit for wives and three-tenths of a unit for husbands. Therefore, hypothesis 3 was supported for both husbands and wives.

Hypothesis 4 results: Daily stressors and marital quality. Hypothesis 4 states that daily stressors will be negatively correlated with marital quality for both husbands and wives. Figure 3 shows that there was a significant negative relationship between amount of daily stress and marital quality for both wives ($\beta = -.43, p < .001$) and husbands ($\beta = -.45, p < .001$). For every unit of increase in daily stress, both husband and wife relationship quality decreased by two-tenths of a unit. Therefore, hypothesis 4 was supported for both husbands and wives.

Hypothesis 5 results: Daily uplifts and marital quality. Hypothesis 5 states that daily uplifts will be positively correlated with marital quality for both husbands and wives. As seen in Figure 4, husband uplifts was positively related to husband marital quality ($\beta = .19, p < .05$) and wife marital quality ($\beta = .40, p < .001$). For every increase in one unit of daily uplifts, both wife and husband marital quality increased by one-tenth of a unit. Therefore, hypothesis 5 was confirmed for both husbands and wives.

Hypothesis 6 results: Partner effects from daily stress to marital quality. Hypothesis 6 states that partner effects from wife daily stress will be negatively related to husband relationship quality and husband daily stress will be negatively related to wife relationship quality, even when controlling for the relevant actor effects. As shown in Figure 3, there was not a significant relationship between wife daily stress and husband marital quality ($\beta = -.05$). The relationship between husbands' daily stress and wife marital quality was also not significant ($\beta = -.12$). Therefore, hypothesis 6 was not supported.

Hypothesis 7 results: Partner effects from daily uplifts to marital quality. Hypothesis 7 states that partner effects from wife daily uplifts will be positively related to husband marital quality and husband daily uplifts will be positively related to wife marital quality, even when controlling for the relevant actor effects. Figure 4 shows that husband daily uplifts was not significantly related to wife marital quality ($\beta = .09$). However, wife daily uplifts was positively related to husband marital quality ($\beta = .25, p < .01$). For every unit of increase in wife daily uplifts husband marital quality increased by one-tenth unit. Therefore, hypothesis 7 was partially supported in there was a partner effect for husband marital quality but not for wives.

Hypothesis 8 results: Uplifts and stresses as mediators between respite care and marital quality. Hypothesis 8 states that the relationship between respite care and marital quality will be significantly mediated by daily stresses and uplifts. Following Preacher and Hayes (2008) guidelines, bias corrected bootstrapping with 2000 draws was used to test whether four indirect paths in Figure 3 evidenced significant mediation effects and whether mediation for the four indirect paths in Figure 4 was significant. The standardized indirect effect of .082 showed that wife daily stress significantly mediated the path from hours of respite to wife marital quality (95% *CI* [.021 - .234], $p < .01$), and husband daily stress significantly mediated the paths from hours of respite to husband marital quality ($\beta = .09$, 95% *CI* [.019 - .256], $p < .01$). Mediation was not statistically significant for the other two indirect paths in Figure 3 and was not significant for any of the four indirect paths in Figure 4. Hypothesis 8 was partially supported with wife daily stress mediating the relationship between hours of respite and wife marital quality and husband daily stress mediating the relationship between hours of respite and husband marital quality.

Discussion

This study examined the role of husband and wife stress and uplifts as possible mediating variables of the relationship between respite care and quality of marriage for couples with a child with DS. 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

Kersh et al. (2006) found social supports, such as respite care, to be a predictor of marital quality in parents who have a child with a developmental disability. Likewise, Robertson et al. (2011) concluded that respite care may have a beneficial impact on couples' overall well being, including reduced stress, decreased exhaustion, and a sense of renewal. The results of this study do not support these conclusions, as respite care was not directly correlated with marital quality for husbands or wives. However, these results do suggest that having a child with Down syndrome may not greatly impact marital quality.

While comparing the marital quality of parents who have a child with ASD to those parents who have a child with Down syndrome, Santamaria, Cuzzocrea, Gugliandolo, and Larcán (2012) found that the marital quality of the parents of a child with Down syndrome was not as greatly negatively impacted as those parents who have a child with ASD. In the current study, 3.6% of husbands and 9.8% of wives were in the distressed marriage range as determined by the RDAS. This suggests that the marital quality of parents of a child with Down syndrome is similar to the general population. It is possible that respite care did not directly correlate to marital quality because there were not many couples that were distressed in their marriage. It is also possible that having a child with Down syndrome does not negatively impact marital quality compared to couples who have a child with ASD, which will be discussed more in the "Down syndrome advantage" section.

Reflections on the Relationship of Respite Care and Stress

Mullins et al. (2002) found that respite care lowered stress for parents, consistent with the findings of the current study that respite care was negatively related to both wife and husband stress. This means that as the hours of respite care increased, the levels of stress experienced by

both wife and husband decreased. The Mullins et al. (2002) study was unique in the fact that the child with a developmental disability (including Cerebral Palsy, Down syndrome, and mental retardation) was admitted to inpatient respite care for 24 hours for 3-7 days. While stress was significantly lower after the brief respite care, it was shown that the parents stress levels had returned to high stress levels after six months. Respite care, as provided to the participants in the present study, occurred more consistently (e.g., weekly, daily) and measures built in supports to the families, such as respite care provided by grandparents and older siblings. Results imply that respite care provided on a regular basis can significantly decrease levels of stress for both husbands and wives and in return increase marital quality.

While respite care did not directly predict marital quality, it was related indirectly through both husband and wife stress. The results of this study show that wife and husband stress was negatively related to marital quality. This means that as respite care increases, stressors decrease and in turn marital quality increases. Similarly, Gallagher and Whiteley (2012) showed that parents who have social support function better psychologically and physically. As parents receive social support, such as respite care, they experience a decrease in stress and are better able to cope. The finding that respite care can decrease stress and, in turn, increase marital quality offers parents a strategy for increasing and maintaining marital quality.

Reflections on the Relationship of Uplifts and Marital Quality

In this study, wife uplifts as well as husband uplifts were positively correlated with marital quality. Not only was wife uplifts positively correlated with wife marital quality, but it was also positively correlated with husband marital quality. The more perceived uplifts the wife has, the better marital quality both the wife and husband report. Berge, Patterson, and Rueter (2006) found that parents who focus on the negative aspects of having a child with a disability

and focus on how it negatively impacts the family have overall lower levels of marital satisfaction. In addition, Robertson et al. (2011) found that respite care can provide mothers and fathers who have a child with a developmental disability with the time to participate in uplifting events. These uplifts, in turn, correlate with positive mental health outcomes and better abilities to cope with stressful life events. This study supports these results and shows that increased perceived uplifts could increase marital quality.

While uplifts were positively correlated with marital quality in the current study, it was not correlated with respite care for either husbands or wives. This may be due to a number of reasons. First, the uplift scores from the sample were already fairly high, meaning that both husbands and wives reported a high number of items as uplifts and that the intensity of their uplifts was also fairly high. Therefore, the hours of respite care may not have been large enough to impact the uplifts score. Second, the activities performed while receiving respite care may not impact uplifts. Future research may consider what each parent is doing during provided respite care and if it could be considered an uplifting event.

Reflections on the Mediating Roles of Stress and Uplifts

Previous research indicates that families who have a child with Down syndrome report higher levels of stress and lower levels of adaptability and coping skills compared to families with typically developing children (Hodapp & Urbano, 2007). A notable finding in the current study shows that stress partially mediated the relationship between the amount of respite care and marital quality. Respite care potentially allows couples the time needed to spend together and accomplish chores and other duties. This can lower stress and, in turn, may increase marital quality. Norlin and Broberg (2013) suggested that having a child with a disability may decrease couples' ability to support and collaborate with each other. Respite care may provide the time

couples need to spend together in order to build the relationship they need to better cope with the stresses they face.

Regarding uplifts, studies have found that having social supports outside of familial relationships can increase the mental health of parents caring for a child with a disability (Gallagher & Whiteley, 2012). The current study did not find uplifts to be a mediator between respite care and marital quality. It could be that husbands and wives may have different sources of uplifts that impact their marital quality that were not measured. Likewise, since this study is correlational, parents who perceive more uplifts in their lives might be less likely to seek respite care services. Additional studies may provide more insight to these relationships.

Parents of a Child with Down Syndrome and ASD

Although it is not possible to make firm conclusions about the population of parents who have a child with ASD in Harper et al.'s (2013) study and the population of parents who have a child with Down syndrome, it is interesting to describe the typical characteristics of the populations in these two studies.

The typical couple who has a child with Down syndrome from this study is 39 (husbands) and 37 (wives) years old. Of the couples surveyed, 57% reported receiving respite care. They receive an average of 5-6 hours of respite care a week. Of the different forms of respite care, grandparents provided most, with the least amount being provided by an outside agency. Overall, the majority of couples (87.4%) reported being satisfied or highly satisfied with the respite care they received. This could possibly mean that older siblings are providing the respite care. Husbands reported average marital quality, as measured by the RDAS, was 62.70 and wives were 60.59, with 3.6% of husbands and 9.8% of wives being in the distressed marriage range (cut-off scores below 48).

The typical couple who has a child with ASD from the Harper et al. (2013) study is 39 (husbands) and 38 (wives) years old. The couples reported receiving an average of 6-7 hours of respite care a week. Of the different forms of respite care, grandparents provided most, with extended family providing the least amount. Husbands RDAS score was 58.45 and wives was 58.87, with 14.3% of husbands and 15.4% of wives in the distressed marriage range.

Reflections on the Down Syndrome Advantage

While the current study did not investigate the “Down syndrome advantage” specifically, it did yield data that can be examined. Research has found that families who have a child with Down syndrome experience less burden and stress as compared to those with other disabilities, especially autism (Blacher & McIntyre, 2006; Urbano & Hodapp, 2007). In the current study, husbands and wives endorsed slightly over 50% of the 53 items as stressful, based on the stress frequency scores, placing severity scores in the moderate range. In a similar study conducted by Harper et al. (2013), couples who have a child with ASD endorsed slightly over 60% of the 53 items as stressful, indicating the severity scores were relatively high. This means that couples who have a child with ASD endorsed 10% more items as stressful compared to couples who have a child with Down syndrome.

Similar results are found when comparing marital quality. According to Harper et al. (2013), 14.8% of husbands and 16.7% of wives, as measured by the RDAS, reported being in a distressed marriage. The current study found only 3.6% of husbands and 9.8% of wives who have a child with Down syndrome to be in a distressed marriage. When comparing RDAS scores obtained from Harper et al. study (2013) and the current study, husband RDAS scores were significantly lower for ASD than DS ($t = -2.88$, $df = 211$, $p < .01$). There was no statistically significant difference for RDAS scores when comparing wives who have a child ASD and wives

who have a child with Down syndrome. Overall, husbands who have a child with Down syndrome rated their marriages as less distressed as compared to those who have a child with ASD. Future studies should explore this concept further with more specific designs to measure the “Down syndrome Advantage.”

Additionally, respite care had a direct effect on marital quality for parents of children with ASD (Harper et al., 2013), while the current study shows that respite care did not have a direct effect on marital quality for parents of children with Down syndrome. This raises the question on how respite care impacts parents of children with different disabilities. While parents who have a child with ASD may benefit from respite care, it may be that parents who have a child with Down syndrome would benefit from other services and supports not provided by respite care.

Limitations

There were several limitations related to this study. This study was not a random representative sample so caution should be taken in generalizing the findings to other husbands and wives raising a child with Down syndrome. The couples were also volunteers who found the invitation to participate in the study through advertising by Down syndrome related websites, social media websites, or organizations serving children with Down syndrome. Another limitation is that the sample was mostly Caucasian, so findings should not be generalized to couples of other races. A third limitation is that the study was questionnaire-based where the parents were expected to complete the questionnaire separately without communicating results with each other, but there was no monitoring to ensure that this was done as directed. Another limitation was the limited number of couples who reported receiving respite care in this study. With this, another limitation may be related to the measure of amount of respite care. There are

no generally accepted, standardized measures of respite care, so the self-report method used in this study may have certain biases related to self-reporting. This study was cross-sectional so no inferences can be made about the causation among the variables.

Implications for Further Research

The findings of this study raise several questions. One question is why respite care did not have a direct effect on marital quality and what, if anything, would work to increase marital quality. Why has respite care been shown to directly impact marital quality in parents who have a child with ASD, but not Down syndrome? Would an increase in respite care make a difference on marital quality for families raising children with Down syndrome? Studies are needed in order to compare families raising children with ASD and Down syndrome in order to better meet the needs of both groups.

In regards to respite care specifically, the current study found that respite care reported was provided mostly by grandparents and rarely by community agencies. It may be that respite care provided by community agencies are difficult for families to access or that parents are reluctant to ask for respite care help by neighbors, friends, or others in the community. Research regarding these factors may be beneficial. There was also a significant correlation that found the hours of respite care to decrease as the number of children in the household increases. This could possibly mean that older siblings are providing the respite care instead of other resources. Another correlation found that respite hours were positively correlated with household income. This implies that the higher the household income, the more respite care they are able to afford. Research regarding these correlations is needed in order to determine who is receiving respite care and what is preventing families from receiving much needed supports like respite care.

Implications for Policy Makers and Practitioners

The findings of this study are relevant for policy makers. Formal respite care is often not available, too high an expense, or in such high demand that it is difficult to acquire for parents of a child with Down syndrome. Informal respite care, often provided by family members and babysitters, is often restricted due to complex family issues and the lack of trained caregivers. The findings of this study indicate that funding to provide more respite care for families who have a child with Down syndrome could indirectly improve the quality of life by increasing uplifts and decreasing stress, which directly impacts marital quality.

There are many implications from these findings that practitioners who work with families who have a child with Down syndrome need to be aware of. First of all, it is important for practitioners, especially those who work in a school setting, to be aware of the challenges and stressors that parents who have a child with Down syndrome face. If respite care was a part of their child's Individualized Education Plan (IEP) and the funding was provided to the schools to support the students, parents may experience an increase in uplifts, a reduction in stress, and an overall increase in marital quality. It is important that parents be made aware of the benefits of respite care. Non-profit groups and community organizations can work hand-in-hand with local schools to provide respite care to families in need. Additionally, these organizations can provide qualified and highly trained individuals. These organizations could also be used to train family members so that the parents are comfortable leaving their child with Down syndrome and so there are numerous respite care providers to support the family.

Conclusion

Both mothers and fathers who have a child with Down syndrome are not fully represented in research regarding parenting children with Down syndrome. As continued

research exposes the challenges and stressors faced by these families, it is important to understand their unique experiences and needs. The findings of this study showed that respite care is related to perceived stress and uplifts which, in turn, is related to marital quality for both husbands and wives who have a child with Down syndrome. This relationship is directly mediated through perceived stressors. Respite care helps reduce stress, which can help increase marital quality. Our findings contribute to the literature regarding parenting children with Down syndrome and the need to provide respite care to these families.

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Table 1

Demographic Characteristics of Husbands and Wives (N=112 husbands, 112 wives) of Children with Down Syndrome (DS)

Variables	Husbands Mean (<i>SD</i>)	Wives Mean (<i>SD</i>)
Age	39.06 (8.53)	37.61 (8.39)
Length of Marriage	10.95 (7.66)	10.95 (7.66)
Number of Children	2.65 (1.25)	2.65 (1.25)
Annual Household Income	\$64,387 (\$25,278)	\$64,387 (\$25,278)
	Percentages	
Relationship Status		
Both biological parents of child w/DS	99.1%	96.4%
Remarried, living w/ biological child w/DS	0.9%	3.6%
Distressed Relationship (determined by RDAS cut off of 48)	3.6%	9.8%
Education		
Less than High School	5.4%	0.0%
High School Graduate	18.8%	9.8%
Completed Some College	28.6%	40.2%
Bachelor's Degree	25.0%	33.0%
Master's Degree	19.6%	15.2%
Doctorate/Professional Degree	2.7%	1.8%
Race		
American Indian/Alaska Native	1.8%	0.9%
Hispanic or Latino	7.1%	5.4%
Black or African American	2.7%	1.8%
Asian	0.9%	2.7%
Native Hawaiian/Pacific Islander	0.0%	0.0%
White	87.5%	88.3%
Other	0.0%	0.9%
Geography		
Canada	0.9%	0.9%
Central	21.4%	21.4%
East Coast	4.5%	4.5%
Mid Atlantic	0.9%	0.9%
Midwest	7.2%	7.2%
Rocky Mountains	30.4%	30.4%
South	24.1%	24.1%
Southwest	1.8%	1.8%
West Coast	8.9%	8.9%

Table 2

Demographic Characteristics of Children with Down Syndrome (N=297, 167 males and 130 females in 112 families), Their Siblings, and Respite Care Provided

	Males		Females		Combined	
	Down syndrome	No Diagnosis	Down syndrome	No Diagnosis	Down Syndrome	No Diagnosis
Birth Order of Child						
1 st	23	34	21	30	44	64
2 nd	14	35	20	21	34	56
3 rd	12	20	11	14	23	34
4 th	10	5	2	8	12	13
5 th	1	3	2	1	3	4
6 th	1	0	1	0	2	0
7 th	1	0	0	0	2	0
8 th	0	1	0	0	0	1
Age Mean (SD)	9.81 (6.94)	11.98 (5.65)	9.18 (6.22)	12.06 (7.68)	9.51 (6.62)	12.01 (7.14)
% Receiving Respite	55.5%		58.1%		57.2%	
Type of Respite						
Grandparents	38.7%		14.9%		68.3%	
Extended Family	11.3%		22.5%		22.2%	
Babysitter	25.8%		18.7%		34.9%	
Agency	11.3%		22.1%		12.7%	
Multiple	12.9%		21.8%		22.0%	

Table 3

Correlations, Means, Standard Deviations for All Measured Variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1.WRespite Hrs.	1.0													
2.HRespite Hrs.	.83***	1.0												
3.WStress Severity	-.20*	-.18*	1.0											
4.WStress Frequency	-.14	-.17*	.87***	1.0										
5.HStress Severity	-.17*	-.19*	.63***	.54***	1.0									
6.HStress Frequency	-.19*	-.15	.57***	.56***	.87***	1.0								
7.W Uplifts Intensity	.04	-.10	-.36***	-.29***	-.24**	-.21**	1.0							
8.W Uplifts Frequency	.07	-.05	-.31***	-.13	-.21**	-.14	.90***	1.0						
9.H Uplifts Intensity	.13	.10	-.29***	-.30***	-.18*	-.19*	.61***	.55***	1.0					
10.H Uplifts Frequency	.15*	.16*	-.22**	-.19*	-.15*	.01	.49***	.51***	.87***	1.0				
11.WRDAS	.15*	.09	-.43***	-.37***	-.34***	-.35***	.40***	.36***	.20*	.15	1.0			
12.WAnx Attachment	-.12	-.11	.36***	.38***	.27***	.28***	-.21**	-.14	-.04	-.01	-.58***	1.0		
13.WAvoid Attach.	-.15*	-.06	.32***	.28***	.22**	.24**	-.28***	-.24**	-.11	-.05	-.73***	.67***	1.0	
14.HRDAS	.02	.07	-.33***	-.40***	-.46***	-.47***	.40***	.33***	.34***	.27***	.67***	-.50***	-.56***	1.0
15.HAnx Attachment	-.06	-.07	.31***	.38***	.37***	.35***	-.18*	-.13	-.18*	-.17*	-.54***	.52***	.59***	-.58***
16.HAvoid Attachment	-.04***	-.05	.19*	.30***	.24**	.23**	-.25**	-.12	-.27***	-.27***	-.48***	.48***	.47***	-.60***
17.H Age	-.08	-.09	-.04	-.05	-.01	.00	.08	.05	.09	-.08	.05	.06	.09	-.04
18.W Age	-.08	-.08	.02	.01	-.01	-.00	.06	.08	-.06	-.10	.12	.07	.08	-.03
19.H Education	.07	.11	-.13	.02	-.17*	-.01	.09	.17*	.09	.06	.20**	-.10	-.12	.05
20.W Education	.14	.15*	.05	.12	-.01	.04	.08	.06	-.06	-.13	.14	.02	.04	-.17*
21.Household Income	.20*	.17*	-.20**	-.07	-.22**	-.14	-.17*	.09	-.03	-.05	.01	-.06	.01	-.05
22.H Race	-.10	-.04	.03	.01	.05	.04	.10	.12	-.14	-.15	.00	-.05	.06	-.07
23.W Race	-.07	-.01	-.05	-.07	-.03	-.06	-.14	-.05	-.03	-.06	.07	-.02	-.03	.12
24.Length of Marriage	-.10	-.11	-.08	-.04	.07	.10	.22**	-.01	.02	.01	.05	.03	.06	-.07
25. # of Children	-.18*	-.13	.10	.08	.15*	.17*	.15	.12	.10	-.04	.07	.04	.05	.05
<i>M</i>	5.45	5.61	99.89	27.76	93.25	25.59	111.75	30.08	109.74	31.53	60.59	40.22	46.70	62.70
<i>S.D.</i>	9.10	10.5	24.81	10.23	24.16	11.64	27.35	10.02	25.74	9.82	9.98	19.72	25.29	8.63

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

Table 3. Continued

	15	16	17	18	19	20	21	22	23	24	25
15.HAnx Attachment	1.0										
16.HAvoid Attachment	.60***	1.0									
17.H Age	.01	.08	1.0								
18.W Age	-.04	.09	.92***	1.0							
19.H Education	.09	-.03	.21**	.16*	1.0						
20.W Education	-.05	.11	.16*	.20*	.51***	1.0					
21.Household Income	-.04	.13	.22**	.33***	.45***	.39***	1.0				
22.H Race	.04	-.09	.06	-.12	-.14	-.16*	-.09	1.0			
23.W Race	.03	-.07	.05	-.05	-.07	-.18*	.08	.31***	1.0		
24.Length of Marriage	.02	.15	.68***	.61***	.27***	.04	.33***	-.10	-.01	1.0	
25. # of Children	-.03	-.06	.10	.09	.08	-.06	.13	-.21**	-.06	.35***	1.0
<i>M</i>	44.77	43.07	39.06	37.61	N/A	N/A	\$64,387	N/A	N/A	10.89	2.65
<i>S.D.</i>	22.52	19.57	8.53	8.39	N/A	N/A	\$25,278	N/A	N/A	7.74	1.25

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

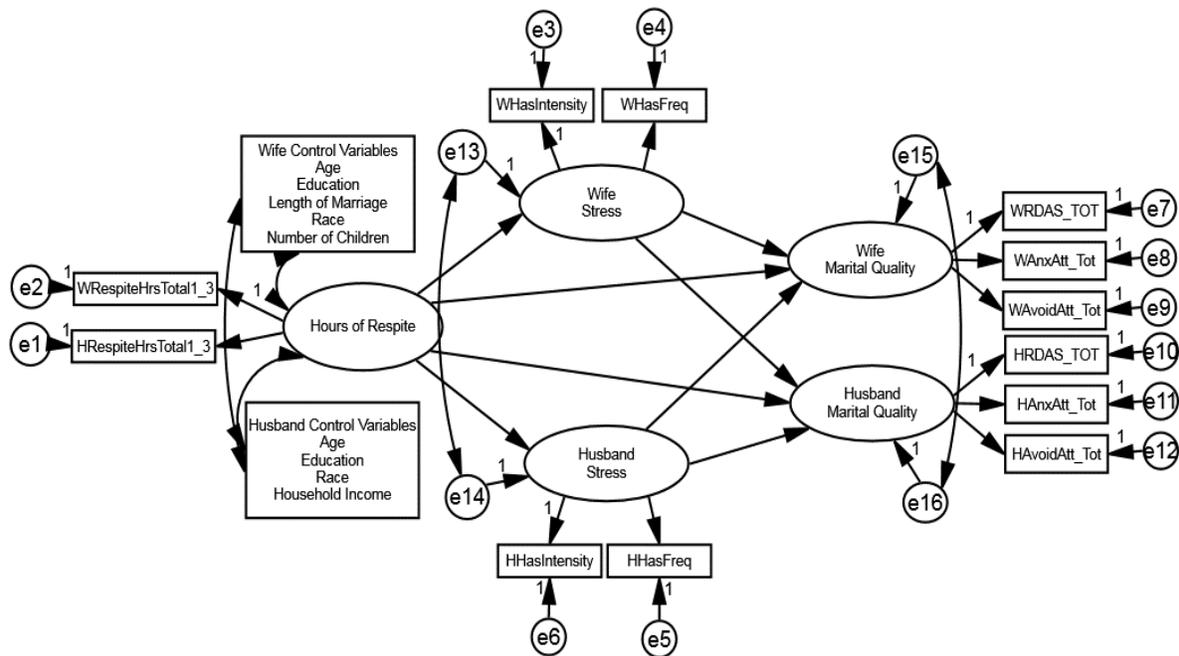


Figure 1. Hypothesized measurement and structural equation model with hours of respite care predicting wife and husband marital quality with wife and husband stress as potential mediating variables.

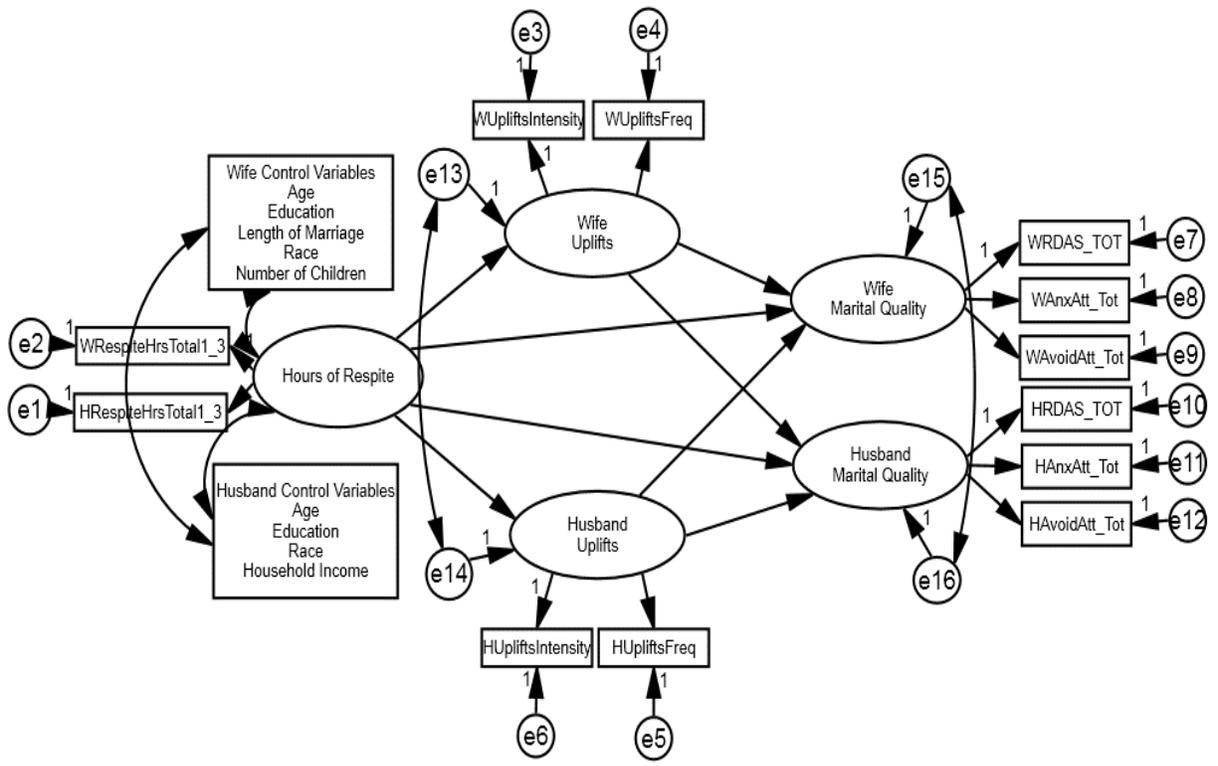
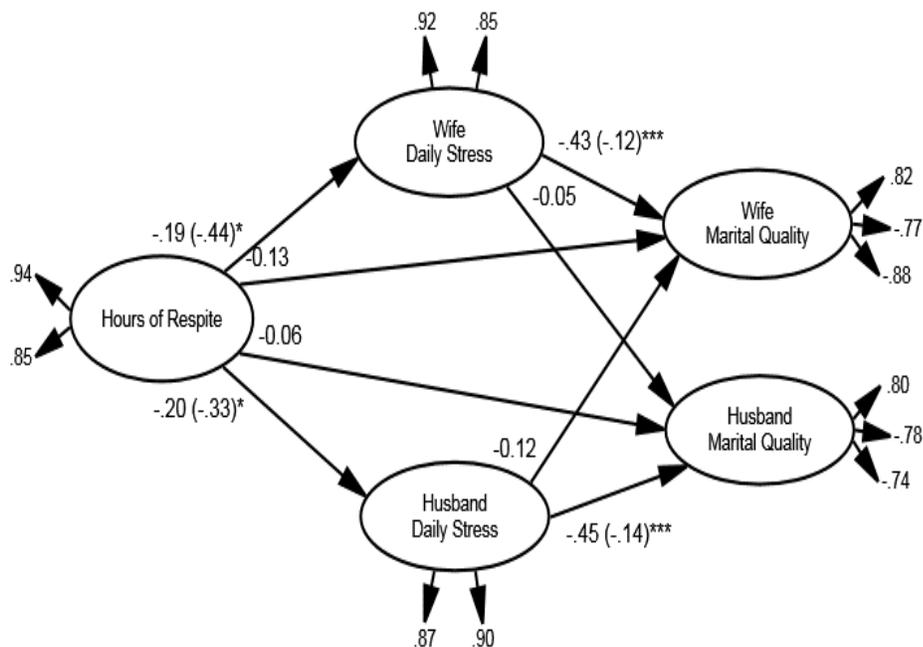


Figure 2. Hypothesized measurement and structural equation model with hours of respite care predicting wife and husband marital quality with wife and husband uplifts as potential mediating variables.

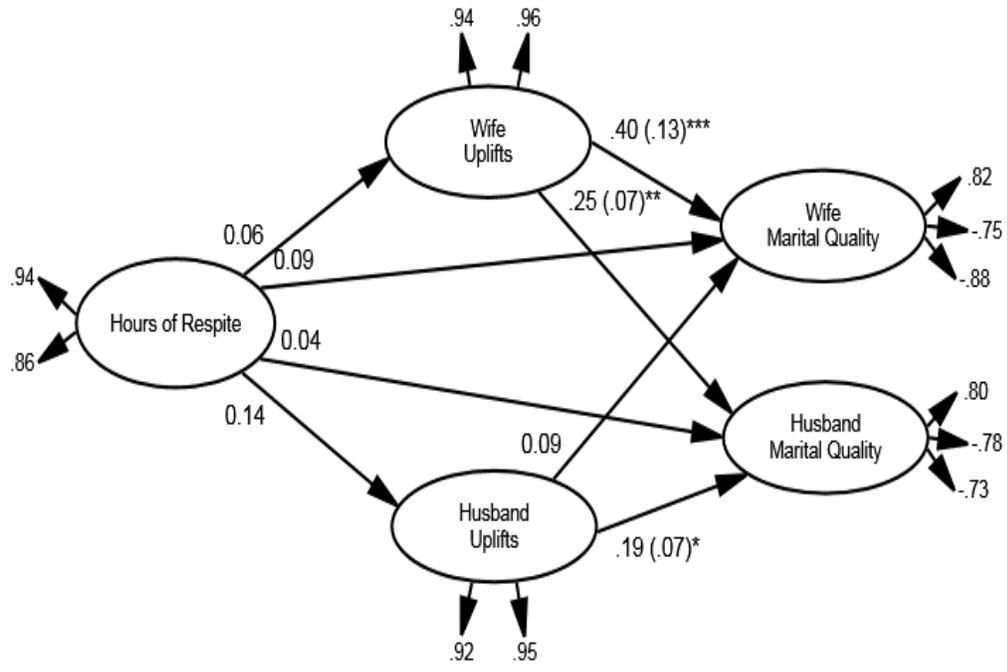


* $p < .05$, ** $p < .01$, *** $p < .001$

$\chi^2 = 39.98$, $df = 33$, $p = .22$
 $CFI = .990$, $RMSEA = .04$, $SRMR = .05$

Figure 3. SEM results with respite hours predicting wife and husband marital quality with wife daily stress and husband daily stress as mediating variables.

Note. Unstandardized beta-coefficients appear in parentheses, with standardized beta-coefficients appearing outside parentheses. Factor loadings are noted with arrows pointing away from latent variables.



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

$\chi^2 = 40.59, df = 33, p = .17$
 $CFI = .99, RMSEA = .05, SRMR = .05$

Figure 4. SEM Results with respite hours predicting wife and husband marital quality with wife daily uplifts and husband daily uplifts as potential mediating variables.

Note. Unstandardized beta-coefficients appear in parentheses, with Standardized beta-coefficients appearing outside parentheses. Factor loadings are noted with arrows pointing away from latent variables.

APPENDIX A:

Review of Literature

Individuals with developmental disabilities are classified as having deficits in intellectual, physical, and adaptive functioning. In addition to these disadvantages, these same individuals have a heightened risk for developing behavioral problems (Eisenhower, Baker, & Blacher, 2005). This presents a great challenge to families who are caring for a child with developmental disabilities and increases the probability of that child being placed in a residential treatment center. Placement in a treatment center significantly increases the risk of social isolation, failed attempts at unrestricted living, and poor educational and occupational outcomes (Maes, Broekman, Dosen, & Nauts, 2003). The distress that families experience can lead parents to feel frustrated, insufficient, insecure, and cause strain on their marital relationship. It is vital to the health of the family to find resources, such as respite care, that enable them to overcome the many burdens of taking care of a child with developmental disabilities.

Down Syndrome

Down syndrome is among the most identifiable chromosomal developmental disabilities. Developmental disabilities affect around 6,000 babies each year in the U.S. In fact, nearly 1 of every 691 babies is born with Down syndrome (Centers for Disease Control and Prevention, 2012). This makes Down syndrome one of the most prevalent of the chromosomal disabilities. Children who are born with Down syndrome are recognized by a distinct physical appearance. The Gale Encyclopedia of Genetic Disorders describes the physical signs as a flat appearing face; a small head; a flat bridge of the nose; upward slanting eyes; bright speckles on the iris of the eye (brushfield spots); extra folds of skin located at the inside corner of each eye near the nose (epicanthal folds); and a deep crease across the center of the palm (simian crease; Johnson,

2005). In addition, babies with Down syndrome tend to be quiet and less responsive to external stimuli: they often have weak, floppy muscles, which contribute to the slow physical development in infants (Johnson, 2005).

Genetic factors. Down syndrome is unique among most disabilities because it has been linked to a known genetic cause. In 1959, an extra chromosome 21 was identified as the cause of Down syndrome (Sherman, Allen, Bean, & Freeman, 2007). During conception, a baby typically receives 23 chromosomes from each parent, which combines to equal 46 chromosomes. In a baby with Down syndrome, an error occurs and the cells do not reduce to the correct number (23), resulting in a cell that contains an extra chromosome. The extra chromosome in Down syndrome is labeled number 21 and therefore sometimes referred to as Trisomy 21 (Sharp, 2002). This process is called nondisjunction and accounts for about 95% of Down syndrome cases (Johnson, 2005).

Other rare genetic accidents have been known to cause Down syndrome. Approximately 1-2% of Down syndrome cases are caused by abnormal cell division shortly after fertilization, resulting in some cells that have 47 chromosomes and some that have the normal number (Sharp, 2002). In about 3-4% of cases of Down syndrome chromosome 21 somehow breaks and attaches to another chromosome. Each cell contains the normal number of 46 chromosomes, but the extra piece of chromosome results in the symptoms of Down syndrome (Johnson, 2005).

This genetic abnormality has been linked to the increased maternal age at the time of conception (Sherman et al., 2007). According to records in the National Down Syndrome Cytogenetic Register (NDSCR), the estimated prevalence for women to have a child with Down syndrome at the age of 20 is 1 in 1,532 while women over the age of 35 have a 1 in 363 chance of having a child with Down syndrome. The probability increases until, at age 45, women have a

1 in 26 chance of conceiving a child with Down syndrome (Morris, Mutton, & Alberman, 2002). This has become a concern for women who are choosing to have children at increasingly older ages. However, despite the fact that older women have an increased likelihood of having a child with Down syndrome, most children with Down syndrome are born to younger mothers. In fact, nearly 80% of children with Down syndrome are born to mothers under the age of 35 (Down Syndrome, 2001).

Diagnosis. A child with Down syndrome is usually identified at birth through observation of the distinct physical features, such as the flattened face, as mentioned previously (Johnson, 2005). Once suspicion of Down syndrome has been noted, genetic testing can be completed to confirm the diagnosis. A blood sample is usually taken, although analysis can also be done on other types of tissue, in order to examine the discrete chromosomes of that individual. The chromosomes are examined under a microscope where, if the infant has Down syndrome, an extra chromosome will be visible (Sharp, 2002).

In addition, there are a few prenatal tests that are available to women who are pregnant. Due to the slight risk of miscarriage (approximately 1%) that has been documented following these tests, testing is optional. Two tests are currently available, amniocentesis and chorionic villus sampling (CVS). With amniocentesis, fluid from the amniotic sac surrounding the developing fetus is extracted with a long, thin needle and tested. In CVS, a tiny amount of placenta, the organ that provides life-sustaining elements to the developing child, is removed for testing. The chromosomes in these samples are examined to determine if the extra chromosome causing Down syndrome is present. While these tests can diagnose the child with Down syndrome, the results do not provide any information on the severity of the disorder. Couples

may use this information to begin preparing themselves for the arrival of the child, to terminate the pregnancy, or to consider adoption (Johnson, 2005).

Health issues. Families often have to handle many health problems that occur in children with Down syndrome. The co-morbidity of many health issues increases the medical and social cost of services for families raising a child with Down syndrome. In fact, children with Down syndrome receive outpatient and hospitalization services three times more than typically developing children (McGrath, Stransky, Cooley, & Moeschler, 2011). These health concerns correlate positively with the severity of intellectual disability in people with Down syndrome and may result in behavioral changes, adaptive ability, and loss of function (Maatta, Kaski, Taanila, Keinanen-Kiukaanniemi, & Livanainen, 2006). Some of the most common health problems include obesity, cardiac conditions, and auditory and visual problems.

Studies have shown a high prevalence of obesity in individuals who have a developmental disability. Prasher (1995) has found that within the Down syndrome population 31% of males and 22% of females are overweight (defined as having a BMI between 25 and 29), and 48% of males and 47% of females are classified as obese (BMI greater than 30). Overall, the rate of obesity in the Down syndrome population is greater than that of the general population. In addition, the prevalence of obesity in individuals with Down syndrome has been found to increase with age, especially for those individuals who live with families (Melville, Cooper, McGrother, Thorp, & Collacott, 2005).

While the cause of the high rates of obesity is still not known, there are a number of ideas. One hypothesis relies on the fact that individuals with Down syndrome have a lower metabolic rate than those in the general population, which results in the body burning less energy (Chad, Jobling, & Frail, 1990). Another hypothesis is that those with Down syndrome may have

reduced physical activity due to the decreased muscle tone that most experience, making it difficult to exercise. Exacerbating this condition, side effects of different medication and hormonal abnormalities make it difficult to get the physical exercise that individuals with Down syndrome need (Prasher & Shaffulia, 2008).

Another common health problem in those with Down syndrome is heart defects. A recent study found that 54% of those with Down syndrome screened in their clinic had some form of cardiac malformation, the most common of which was patent ductus arteriosus, which accounted for approximately 29% of the cases. Patent ductus arteriosus occurs when a blood vessel located near the heart does not close within 48 hours after birth. The second most common malformation was ventricular septal defect, which is when a hole forms in the muscle wall separating the two ventricles in the heart. This accounts for 27% of the heart problems. The third most common problem was atrial septal defect, which accounted for 13% of health problems. Atrial septal defect occurs when there is a problem with the blood flow from the left atrium of the heart to the right atrium. This can cause chest infections, breathlessness, tiredness, palpitations, and an abnormal heart beat (Vida et al., 2005).

Children with Down syndrome also have a high prevalence of ocular and auditory disorders. In one study, 43% had significant refractive eye errors, including astigmatism, myopia, and hyperopia. By the age of three years old, most children with Down syndrome who have difficulty with vision require corrective lenses or glasses (Stephen, Dickson, Kindley, Scott, & Charleton, 2007). Previous studies have also reported a 38-78% incidence of hearing loss in children with Down syndrome. This could be due to the anatomic abnormalities of the middle ear, which is shaped differently and collapses easily making ear infections and hearing loss more

prevalent. Early diagnoses and aggressive treatments are best for optimal development and functioning (Shott, Joseph, & Heithaus, 2001).

Intellectual disabilities. Individuals with Down syndrome exhibit a wide range of cognitive functioning. Most fall into the mild to moderate range of cognitive disability, having IQ's ranging from 20 to 90 with the mean being 49 (Strickland, 2001). It is often difficult to measure the exact level of cognitive ability as most individuals with Down syndrome have speech, vision, hearing, and physical disabilities that interfere with cognitive functioning (Penna & D'Andrea-Penna, 2009).

The cognitive profile of individuals with Down syndrome varies. In infancy, certain delays do not become prevalent until the child is a few months old, especially in verbal abilities, which are delayed about seven months compared to when typical infants begin to develop verbal abilities (Down Syndrome, 2001). Physical difficulties in vision and hearing may contribute to this delay (Maatta et al., 2006). A meta-analysis showed that poor short-term memory for verbal information has also been found to contribute to the delay in both expressive and receptive language acquisition (Naess, Lyster, Hulme, & Melby-Lervag, 2011).

In addition, recent studies have found a rise in Alzheimer's in older adults with Down syndrome. As individuals with Down syndrome grow older, they often show major cognitive declines and are 20 times more likely than the general population to develop early Alzheimer's disease (Down Syndrome, 2001). The comorbidity of Down syndrome and Alzheimer's has been amplified in recent years by the increased life expectancy of those with Down syndrome and the earlier onset of Alzheimer's in the general population (Maatta et al., 2011). In addition, a frequent history of depression and behavioral problems has been found to precede the onset of dementia (Coppus et al., 2006).

Academic challenges. Due to the delays in cognitive functioning that most individuals with Down syndrome display, there are a number of academic challenges that these children face. Among the most prevalent is their ability to communicate and behave properly in school (Turner, Alborz, & Gayle, 2008). Mainstreaming children who have Down syndrome has been shown to be an effective way of offsetting these disadvantages resulting in higher academic abilities (Turner et al., 2008). In a study comparing adolescents with Down syndrome educated in mainstream classrooms and special education classrooms, no differences were found in the progress for skills in socialization; however, significant improvements in communication skills were found in those educated in the mainstream classroom, including skills in expressive language and literacy abilities, as well as demonstrating fewer behavioral problems (Buckley, Bird, Sacks, & Archer, 2006). Another study that compared mainstream and special education classrooms found that children with Down syndrome achieve higher scores in vocabulary, grammar, and digit span measures when taught in the mainstream classroom (Laws, Byrne, & Buckley, 2000).

Adaptive behavior. Children with Down syndrome develop their adaptive skills much slower and may never reach the same level of development as typical children. Children with Down syndrome appear to reach their peak of development around the age of 12, compared to 10 years old in typically developing children (van Duijn, Dijkxhoorn, Scholte, & Berckelaer-Onnes, 2010). In addition, children with Down syndrome have been found to reach 65% of the maximum ability in tests of adaptive skills, whereas typically developing children reached approximately 90% of the maximum score (van Duijn et al., 2010).

Not only do children with Down syndrome show delayed development, but they also portray a specific profile of adaptive functioning. Researchers have found that children with

Down syndrome have strong skills in self-care and social behavior, but are delayed in motor development and communication skills (Dykens, Hodapp, & Finucane, 2000; Balboni, Pedrassi, Molteni, & Villa, 2001). These delays are especially apparent in expressive communication, as compared to receptive abilities (Dykens, Hodapp, & Evans, 2006). This suggests a general strength in receiving information from the environment but a weakness in verbal expression.

Down syndrome advantage. There has been some debate about the advantage of having a child with Down syndrome as compared to having a child with other disabilities. Most of the studies that focus on the challenges of raising a child with developmental disabilities have concentrated on the specific challenges children with autism produce. For example, they are less compliant, have a more negative effect on parental stress, and are less self-regulated (Hodapp, Ly, Fidler, & Ricci, 2001). While those with Down syndrome are usually portrayed as being able to adjust better socially and exhibit fewer behavioral problems (Hodapp et al., 2001). As such, they are considered much easier to care for and are often referred to as the preferred disability for a child to have. This has been labeled as the “Down syndrome advantage” (Eisenhower et al., 2005).

The “Down syndrome advantage” is a popular belief that children with Down syndrome are easier to care for and raise compared to children with other disabilities. This has been attributed to factors relating to the child and the characteristics associated with the syndrome. Children with Down syndrome typically have characteristics that are absent in other disabilities, such as social competence and a greater responsiveness to people. In addition, the ability to use language and exhibit fewer behavioral problems is believed to prompt positive reactions from parents, family members, and other caregivers (Hodapp et al., 2001).

Research has found that mothers of children with Down syndrome display less depression and have more positive experiences compared to mothers of children with other developmental disabilities (Blacher & McIntyre, 2006). Mothers also report less burden and stress due to caring for a child who has Down syndrome compared to mothers of children with other intellectual disabilities (Seltzer, Krauss, & Tsunematsu, 1993). Increased maternal age, which has been linked to Down syndrome, may play a factor in decreased stress, as higher levels of education, reduced financial stress, and greater child rearing experience better equip parents to cope with the child's disability (Hodapp et al., 2001). Likewise, families of children with Down syndrome have been found to have lower levels of divorce and greater family coping and functioning compared to families who have a child with autism (Urbano & Hodapp, 2007), which may have a reciprocal effect on family functioning and maternal stress.

Familial relationships, especially sibling relationships, also support the "Down syndrome advantage". Children who have a sibling with Down syndrome often have a better relationship with their sibling compared to children with autism. This may be related to the personal characteristics associated with Down syndrome as siblings relate to their brother or sister's calmer personality and lower levels of behavioral problems (Hodapp & Urbano, 2007). Likewise, siblings report that childhood experiences are not negatively affected by having a sibling with Down syndrome. When compared, siblings of typically developing children and Down syndrome both account no differences in engagement in the world outside the family, with peers, and in their academic performance (Cuskelly & Gunn, 2006). In fact, having a sibling with Down syndrome has a positive effect on typically, developing siblings as it contributes to them being more compassionate, caring, and empathetic (Povee, Roberts, Bourke, & Leonard, 2012).

However, this does not mean that familial relationships do not experience complications. When families of children with Down syndrome are compared to families of typically-developing children, the “Down syndrome advantage” diminishes (Hodapp et al., 2001). Research shows that although children with Down syndrome are significantly less likely to display maladaptive behavior compared to children with other disabilities, children with Down syndrome still display far more behavioral problems than typically developing children from the general population. Such behaviors include, but are not limited to, stubbornness, oppositionality, inattention, speech problems, difficulties concentrating, attention seeking, and impulsivity (Dykens, 2007). In addition, compared to families with non-disabled children, families with a child with Down syndrome report higher levels of stress, adjustment difficulties, and poor coping (Hodapp & Urbano, 2007). This suggests that families of children with Down syndrome display malfunction and could benefit from supports in order to reduce the burden often felt when caring for a child with disabilities.

Families of Children with Down Syndrome

This section gives an overview of the typical family who has a child with Down syndrome including different characteristics of the family, stressors, and marital quality of the parents.

Characteristics of families. Having a child diagnosed with a disability greatly impacts the dynamics and functioning of the family. Parents may react to the birth of their child with a sense of loss and mourning for the “perfect” child they hoped for (Emde & Brown, 1978; Wright 2008). Discovering their child has Down syndrome can also have a major effect on the family’s future goals and dreams. While most families find strategies to cope with having a child with Down syndrome, there are many challenges in accepting the child as part of the family. Families

often have to adapt family activities to suit the child's skills and abilities, energy levels, attention span, and personal interests. Likewise, families may need to adjust holidays and outings to consider the safety and care requirements of the child (Povee et al., 2012).

Povee et al. (2012) found factors relating specifically to the child that also impact family functioning. Family activities are often restricted due to maladaptive behavior of the child such as running away, not listening, tantrums, and social inappropriateness. In addition, low functional ability of the child with Down syndrome is another factor that affects families. This puts added demands on the parents, as they are responsible for the child's transportation, dressing, feeding and toileting, etc. The care demands of the child are described by families as being stressful and exhausting, a financial burden, and limiting in the time that could be spent with other family members. In addition, many parents feel a loss of their own life, as the child with Down syndrome would always be dependent on them.

Parents are also concerned about the effect that the child will have on the overall family structure. Povee et al. (2012) found that many parents and caregivers of children with Down syndrome felt that the most negative impact on having a child with Down syndrome was on the other siblings, as they believed their other children receive less attention, have a restricted social life, and are often relied on to be caretakers of their sibling with Down syndrome. This is compounded by the lack of spontaneity and freedom the family experiences due to the needs of the child with Down syndrome and the lack of appropriate childcare to allow the family some freedom.

Stressors. Over time parents may adapt psychologically to having a child with disability; however, both parents experience mental stress related to the child's disability. Numerous studies have demonstrated that parental stress increases as the demands of the child increases

(Hauser-Cram et al., 2001). The stress for the mother may be different than the stress the father experiences. Studies have demonstrated that mothers report higher stress levels related to their parental roles and childcare and that fathers report more stress over their feelings or lack of attachment to the child (Bailey, Golden, Roberts, & Ford, 2007; Krauss, 1993). Fathers also report higher stress in regards to the social acceptability of their child with disabilities (Keller & Honig, 2004).

Not only does the stress of raising a child with disabilities affect the parent's mental coping, but their physical functioning as well. Parents caring for children with developmental disabilities have been found to have lower immune and neuroendocrine functioning (Gallagher, Phillips, Drayson, & Carroll, 2009; Lovell, Moss, & Wetherell, 2012a). Greater social support for these parents has been found to predict better psychological and physical functioning and has specifically been associated with decreases in blood pressure (Gallagher & Whiteley, 2012).

Much of the most recent research has focused primarily on the hardships that mothers who have a child with developmental disabilities encounter. Multiple studies have demonstrated that mothers who have a child with a disability are the primary caregiver and person responsible for their children's daily needs, health, development and participation: this is true in over 95% of family situations (Bourke-Taylor, Pallant, Law, & Howie, 2012). Looking at mothers who are caregivers, Crowe and Florez (2006) found that those who have a child with a disability spend a mean of 27.5 hours a week in child care activities as compared to the 18 hours a week spent in child care of mothers who do not have a child with a disability. This increased caregiver burden has been linked to amplified depressive symptoms in mothers who have a child with a disability as compared to fathers and mothers who do not have a child with a disability (Bailey et al.,

2007). Depressive symptoms, and other negative feelings, can have a damaging impact on the marital quality of mothers and fathers.

Marital quality. Marital quality is perceived as the feelings, both negative and positive, that the wife or husband develops from the couple's relationship. These feelings involve conflicts, sharing of activities, confidence, and expression of affection (Norlin & Broberg, 2013). Having a child with a disability has been found to have a direct negative influence on the marital satisfaction of the parents, especially for mothers (Norlin & Broberg, 2013). Within the parental relationship, there is a positive relationship between marital quality and the amount of coparenting in families who have a child with a disability (Norlin & Broberg, 2013). Coparenting may help to relieve stressful situations. However, having a child with a disability may place a strain on the parents' ability to support and cooperate with each other, and therefore coparent (Norlin & Broberg, 2013). Lower levels of marital satisfaction are especially evident when the parents view the child's condition in a negative light and see the condition as negatively impacting their family and overall functioning (Berge, Patterson, & Rueter, 2006).

The results of studies examining how having a child with Down syndrome affects the marital relationship between the husband and wife have been mixed. Most studies have focused on comparing parents of children with Down syndrome with parents of children with autism. Following along the lines of the "Down syndrome advantage," most of these studies find that the marital quality of parents who have a child with autism is greatly affected, while parents of children with Down syndrome do not have as many negative consequences in their marriage (Santamaria, Cuzzocrea, Gugliandolo, & Larcan, 2012). One study found that the marital relationships of families who have a child with Down syndrome were comparable to families who do not have a child with a disability (Povee et al., 2012). Another study (Kersh, Hedvat,

Hauser-Cram, & Warfield, 2006) found that the stress and depressive symptoms of mothers and fathers of a child with Down syndrome do not differ from parents who do not have a child with disabilities. However, those parents who have a child with a disability have lower quality marriages than couples in the general population.

A meta-analysis showed that while past studies may have exaggerated the negative effects of having a child with disabilities in the home, there is still a negative impact on marital relationships in those families who have a child with a disability (Risdal & Singer, 2004). In fact, in studies compared in the meta-analysis there was a 5.97% increase in divorce in families who have a child with disability when compared to families raising typically developing children. While the effect size is small ($d = .21$) it appears to still have a negative effect on the marital relationship of parents. Given that families do experience marital strain it is important to provide appropriate family supports that will improve marital outcomes in families who have a child with a disability (Risdal & Singer, 2004).

Services for Families of Children with Down syndrome

This section gives an overview of the services available for families who have a child with Down syndrome including support groups, respite care, and the availability of respite care.

Support groups. A popular type of support for families who have a child with disabilities is family-centered support. Family systems theory advocates approaching the family as a whole while encouraging a commitment to family choice and decision-making. The family is seen as an interactive structure in which changes in one family member affect the rest of the family (Hauser-Cram et al., 2001). Families are encouraged to be involved in the intervention, in learning new skills, and in strengthening the support networks that are available to families. The

whole purpose of family support is to strengthen family functioning in order to improve parent and sibling knowledge and the ability to effectively interact with the child with disabilities.

Respite care. Respite care can be a positive tool in helping families cope with the challenges they face. Respite care involves giving the family, specifically the parents, a limited break from the responsibilities in caring for their child with disabilities. This could include having someone come into the home to care for the child or taking the child out of the home to provide the family with a short break. In a meta-analytical study, Robertson et al. (2011) found that respite care can have a beneficial impact on parents' well being. Specific benefits include reduced stress, rest and relaxation, a sense of relief, freedom to do something for themselves, alleviating exhaustion, and promoting a sense of renewal.

Many have called for the need for respite care as a way to relieve parental stress, anxiety, and depression in caring for a child with disabilities. One study investigated factors that decrease depression and anxiety in mothers who have a child with a developmental disability (Bourke-Taylor et al., 2012). The results of this study found that participation in health promoting activities, time management, prioritization of oneself, and shared caring of the child with supportive others have the highest correlation with positive mental health outcomes (Bourke-Taylor et al., 2012). Respite care was suggested to provide time for mothers to get away and complete many of these health-promoting tasks.

In fact, respite care has been shown to have positive effects on parental health and family functioning. In a longitudinal study (Mullins, Aniol, Boyd, Page, & Chaney, 2002), parental stress and functional ability were measured before and after their child with developmental disabilities received brief (3-7 days) respite care. Parental stress as well as psychological distress was significantly lower when the child was discharged. However, those levels rose back to

admission levels six months later, suggesting that continued respite care is effective in helping parental and familial functioning. Respite care did increase the levels of familial functional ability, showing that both children and parents were able to operate better in the home after receiving respite care (Mullins et al., 2002).

The need for respite care does not depend on the age of the child or the age of the mother. Slight differences were found when comparing the emotional well being of mothers of adolescents and adults with autism (Barker et al., 2011). Researchers compared anxiety and depression levels of younger mothers and mothers who have an adult with Autism at home. Depressive symptoms did not change drastically across a ten-year period (Barker et al., 2011). These authors suggested that support for mothers in the form of respite care or community living for adolescents and adults with developmental and intellectual disabilities would be a great benefit to the well being of the mothers, no matter the age of the child or the mother.

Likewise, respite care can have positive benefits to the parents' perceived marital quality. A recent study found that respite care has great benefits to the marital quality of those who have a child with Autism Spectrum Disorder (Harper, Dyches, Harper, Roper, & South, 2013). These results have also been found in parents who have a child with a developmental disability. Kersh et al. (2006) found that social support was a moderate predictor of the marital quality of parents who have a child with developmental disabilities. This suggests that social factors outside of the home, such as respite care, may be associated with marital quality.

Availability of respite care. The demand for respite care is great in the developmental disability population. In a study comparing the met and unmet needs parents of children with Autism Spectrum Disorder and Down syndrome, two-thirds of both groups reported important needs as not being met (Siklos & Kerns, 2006). Significant unmet needs of parents who have a

child with Down syndrome included: “information about special programs and services available to my child and family (84%)”; “to get a break from my responsibilities (75%)”; “for my child to have friend of his/her own (78%)”. This suggests that parents who have a child with Down syndrome do not feel that the services available are providing adequate social support for their families or their children and that parents do need a break from care of their child (Siklos & Kerns, 2006).

The need for respite care often exceeds the availability of such care. In an examination of the Action for Children program, located in London, which provides short breaks for families who have a child with a disability, respite care was shown to have a positive effect on the families as well as the child (McDermid, Soper, Lushey, Lawson, & Holmes, 2011). However, many of the parents reported that additional breaks would be preferable to the breaks they were already receiving. In addition, two of the facilities that participated in the review had waiting lists and were unable to provide services to families because they were filled to capacity (McDermid et al, 2011).

In addition, the amount of respite care received is often inadequate. The need for respite care is so great that the length of respite breaks available to families have to be rationed (McConkey, Kelly, & Craig, 2011). Parents with children who are severely limited in their daily activities are more likely to report needing respite care, but were refused a childcare program or service. They also reported being more likely to quit work, work fewer hours, or to turn down a job in order to care for their child. Implications of this study are that family-centered care needs to consider the needs of the caregivers and to validate their concerns. Supporting the family in their caregiving roles may result in better health outcomes for children with a disability as well as for their caregivers (Baillargeon, Bernier, & Normand, 2011).

Conclusion

Children with Down syndrome present multiple factors, such as health problems, academic, cognitive, adaptive, and behavioral functioning that poses unique challenges to parents. Not only may this increase parental stress, it may impact family functioning and structure. This can directly impact marital quality between the husband and wife. Having a break from caring for their child with Down syndrome may alleviate some of the stress and increase the marital quality of both husbands and wives. Respite care has been found to reduce stress and increase reported daily uplifts for parents who have a child with ASD. Supporting the family in their caregiving roles may result in increased marital quality between husbands and wives who have children with Down syndrome.

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APPENDIX B:

Recruitment

Dear [insert name],

Recent research has indicated respite care can be beneficial for families raising children with Autism Spectrum Disorders, particularly for marital relationships, where just one hour of weekly respite care has the potential to move a couple from a distressed relationship to one which is satisfactory. However, little research investigates how respite care impacts parents of children with Down syndrome. Researchers at Brigham Young University are studying the relationships between respite care and family functioning of parents who have a child with Down syndrome. We are requesting your help in recruiting participants from your school/organization. You could help by:

- Posting a link on your website that advertises the research,
- Emailing the attached flyer to parents of children with Down syndrome,
- Printing the attached flyer and posting it in your building,
- Printing the attached flyer and sending it home to parents of children with Down syndrome, and/or
- Including the research advertisement in your electronic newsletter.

The attached flyer contains basic information about the research, including a hyperlink to the consent form and online questionnaire. Paper copies of the questionnaire are also available. The only request we are making of you is to help us advertise the research in one or more of the ways listed above.

This research project has been approved by the Institutional Review Board for Human Subjects at Brigham Young University and poses no risks to participants. Participants will be compensated with a \$25 gift card upon completion of the questionnaires.

If you agree to advertise this research project, please complete the attached permission form and return it via email, fax, or postal mail.

Attached you will find the following:

1. Permission form to advertise the respite care study (for you to complete and return to us)
2. Recruitment flyer (for you to distribute)
3. Questionnaires (for your information regarding the study)

At the end of this email you will find a statement you can copy/paste to your website or send as an email to advertise the study. If you have questions about this research, you may contact Tina Dyches, Ed.D. at (801) 422-5045 or the BYU Institutional Review Board Administrator at (801) 422-1461.

Thank you for considering this request.

Sincerely,

Michelle Norton, School Psychology Graduate Student
Tina Dyches, Ed.D., Associate Professor, Department of Counseling Psychology and Special Education

Consent for Organizations

I, _____ (name and title), hereby grant Brigham Young University researchers, Michelle Norton and Tina Dyches, permission to advertise their research regarding parents of children with Down syndrome through our school/organization. We will advertise in the following ways (mark all that apply):

- Posting a link on our website that advertises the research,
- Emailing the attached flyer to parents of children with Down syndrome,
- Printing the attached flyer and posting it in our building,
- Printing the attached flyer and sending it home to parents of children with Down syndrome, and/or
- Including the research advertisement in our electronic newsletter.
- Other: _____

Special considerations (please include any directions or approvals that are specific to your organization/school): _____

Signed: _____

Organization/School: _____

Website url: _____

Date: _____

Please return this form to:

By fax: Dr. Tina Dyches 801-422-0198

By e-mail: tina_dyches@byu.edu

By postal mail:

Dr. Tina T. Dyches

Department of Counseling Psychology and Special Education

340-F MCKB

Brigham Young University

Provo, UT 84602

Statement for Websites/Email

Research Participants Needed for Study of Single Mothers of Children with Autism Spectrum Disorders

Researchers at Brigham Young University are looking for parents of children with Down syndrome to participate in a research study about respite care and family functioning.

- It will take approximately 45-60 minutes to complete the questionnaire.
- Participants will receive a \$25 gift card when they return completed questionnaires.
- Questionnaires can be accessed online or on paper.

For more information about participating in this study, please click the following link:
http://education.byu.edu/down_syndrome_study.html

or contact Dr. Tina Dyches at tina_dyches@byu.edu or (801) 422-5045.

PARTICIPANTS NEEDED FOR
RESEARCH IN
Mothers and Fathers of Children with
Down Syndrome



We are looking for volunteers to take part in a study regarding respite care and family functioning in parents who have a child with Down syndrome.

As a participant in this study, you will be asked to complete an anonymous questionnaire either online or on paper, which will take approximately 45-60 minutes.

In appreciation for your time, you will receive a \$25 gift card.

For more information about this study, or to volunteer for this study, please contact:

Dr. Tina Taylor Dyches
Department of Counseling Psychology & Special Education
340-F McKay Building, Brigham Young University
Provo, UT 84602
(801) 422-5045
tina_dyches@byu.edu

This study has been reviewed by, and received approval through the Brigham Young University Institutional Review Board.

Appendix C: Consent to be a Research Participant

Respite Care and Marital Quality Project

Introduction

This research study is being conducted by Michelle Norton, a School Psychology graduate student at Brigham Young University, to determine how the amount of respite care is related to the quality of marriage and daily hassles/uplifts in parents who have a child with Down syndrome. You and your spouse are invited to participate because you are married and have a child with Down syndrome.

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 postal mail, e-mail, or an online Internet link.
- The questionnaire will include questions regarding your age, length of marriage, household income, family size, about amount of respite care you receive for your child with Down syndrome, daily uplifts/hassles, and your marriage.
- It will take about 45-60 minutes 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.
- You will submit your results using the method you received them.

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 Down syndrome, 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 \$25 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 Michelle Norton (801) 554-2039 or at michellenorton767@gmail.com or Tina Dyches, Ed.D. at (801) 422-5045, tina_dyches@byu.edu.

Questions about your Rights as Research Participants

If you have questions regarding your rights as a research participant, you may contact the Institutional Review Board administrator at (801) 422-1461, A-285 ASB Campus Drive, Brigham Young University, Provo, UT 84602 or <https://orca.byu.edu/irb/>.

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: _____

APPENDIX D:

Measures**Demographic Questions**

1. What is your current relationship status?
 - My current spouse and I are the parents of our child(ren) with Down syndrome.
 - I am divorced from the other parent of our child(ren) with Down syndrome, have remarried, and am living with our child(ren) with Down syndrome.
 - *I am divorced from the other parent of our child(ren) with Down syndrome, have remarried, and am NOT living with our child(ren) with Down syndrome.
 - *I am divorced, separated, or widowed from the other parent of our child(ren) with Down syndrome and have NOT remarried.
 - *I am single (never married).

*If this applies to you please click here for the study for single parents of children with Down syndrome

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?

<ul style="list-style-type: none"> <input type="radio"/> Hispanic or Latino <input type="radio"/> NOT Hispanic or Latino Race 	<ul style="list-style-type: none"> <input type="radio"/> American Indian or Alaska Native <input type="radio"/> Asian <input type="radio"/> Black or African American <input type="radio"/> Native Hawaiian or Other Pacific Islander <input type="radio"/> White <input type="radio"/> Other (list)
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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's degree or completed some college
- Bachelor's degree
- Master's degree
- Doctorate or Professional degree (e.g., M.D., J.D.)

11. Who is the primary caregiver of your child(ren) with Down syndrome?

- Mother
- Father
- Other _____

If you have an additional child(ren) with Down syndrome, please complete the question below for your second child. IF NOT, please skip to Question #2.

			Satisfaction with Respite Care					
	Provides Respite Care?		Amount of WEEKLY time in respite care? Hours/Minutes	Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied
	Yes	NO						
Child 2-Grandparent/s								
Child 2-Extended Family Member								
Child 2-Babysitter								
Child 2-Community Agency								
Child 2-Other? _____								

How many hours a week do child 1 and child 2 receive respite care at the same time?

If you have an additional child(ren) with Down syndrome, please complete the question below for your third child. IF NOT, please skip to Question #2.

			Satisfaction with Respite Care					
	Provides Respite Care?		Amount of WEEKLY time in respite care? Hours/Minutes	Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied
	Yes	NO						
Child 3- Grandparent/s								
Child 3- Extended Family Member								
Child 3- Babysitter								
Child 3- Community Agency								
Child 3- Other? _____								

How many hours a week do child 1 and child 3 receive respite care at the same time? _____

How many hours a week do child 2 and child 3 receive respite care at the same time? _____

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

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

_____hours_____minutes

4. How much time (in hours and minutes) do you usually spend with your spouse in a typical week WHEN YOUR CHILD(REN) 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	2	3	4	5	6	7
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
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 |

Revised Dyadic Adjustment Scale (RDAS)

Most people have disagreements in their relationships. Please indicate below the extent of agreement or disagreement between you and your partner for each item.

	Always Agree (5)	Almost Always Agree (4)	Occasionally Agree (3)	Frequently Disagree (2)	Almost Always Disagree (1)	Always Disagree (0)
1. Religious matters						
2. Demonstrations of affection						
3. Making major decisions						
4. Sex relations						
5. Conventionality (correct or proper behavior)						
6. Career decisions						

	All the Time (0)	Most of the time (1)	More often than not (2)	Occasionally (3)	Rarely (4)	Never (5)
7. How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
8. How often do you and your partner quarrel?						
9. Do you ever regret that you married (or lived together)?						
10. How often do you and your mate "get on each other's nerves"?						

	Every Day (4)	Almost Every Day (3)	Occasionally (2)	Rarely (1)	Never (0)
11. Do you and your mate engage in outside interests together?					

How often would you say the following events occur between you and your mate?

	Never (0)	Less than once a month (1)	Once or twice a month (2)	Once or twice a week (3)	Once a day (4)	More often (5)
12. Have a stimulating exchange of ideas						
13. Work together on a project						
14. Calmly discuss something						

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	3	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		0	1	2	3
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. New 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