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ORIGINAL PAPER

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

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Abstract Parents of children with disabilities are at risk for high stress and low marital quality; therefore, this study surveyed couples ($n = 112$) of children with Down syndrome ($n = 120$), assessing whether respite hours, stress, and uplifts were related to marital quality. Structural equation modeling indicated that respite hours were negatively related to wife/husband stress, which was in turn negatively related to wife/husband marital quality. Also, wife uplifts were positively related to both wife and husband marital quality. Husband uplifts were positively related to husband marital quality. Therefore, it is important that respite care is provided and accessible to parents of children with Down syndrome.

Keywords Actor-partner interdependence model · Down syndrome · Respite care · Marital quality · Stress · Uplifts · Structural equation modeling

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Down syndrome is among the most prevalent chromosomal disabilities, with one out of every 691 babies born with the condition each year (Centers for Disease Control and Prevention 2012). Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21, resulting in deficits in intellectual and adaptive functioning (Sherman et al. 2007). Viewing the disabilities associated with having Down syndrome without considering the associated strengths represents an outdated perspective, and within a family systems model, these strengths and limitations should be considered for the family unit, not for the individual alone.

Uplifts and Stressors of Families Raising a Child with Down Syndrome

Uplifts

Daily uplifts are regular experiences that are perceived as positive. Because children with Down syndrome are often seen as having advantages over those with other disabilities, including a higher level of social competence, responsiveness to people, ability to use language to communicate, and a personality that is caring and gentle (Hodapp et al. 2001), families raising children with Down syndrome may experience more daily uplifts than families raising children with other disabilities.

Advantages exist for parents and for siblings of children with Down syndrome. Mothers of children with Down syndrome have been found to have more positive experiences and display less depression, stress, and caregiver burden compared to mothers of children with other developmental disabilities (Blacher and McIntyre 2006; Seltzer et al. 1993). Siblings of children who have Down syndrome often

have better relationships with their sibling compared to siblings of children with autism. Also, no differences have been found between siblings of typically developing children and siblings of children with Down syndrome in relation to their engagement in the world outside the family, with peers, and in their academic performance (Cuskelly and Gunn 2006).

Stressors

Although some children with Down syndrome may be easier to raise than those with other disabilities, reported challenges must be considered. Compared to families who do not have a child with a disability, families rearing a child with Down syndrome report overall higher stress levels, more adjustment difficulties, and poorer coping abilities (Hodapp and Urbano 2007).

In addition to general stressors, these families may experience daily stressors, which are frequent experiences perceived as annoying or bothersome. Because of these daily stressors, families may need to adapt or restrict their daily activities to meet the unique concerns of their child (Povee et al. 2012). Also, additional parental stress is related to the increased care demands of the child (Hauser-Cram et al. 2001), including the daily responsibilities related to the child's transportation, dressing, feeding, toileting, and other care needs (Povee et al. 2012).

These stressors may place a burden on the marital relationship. The distress experienced by parents of children with developmental disabilities, including those with Down syndrome, has been found to be negatively related to marital quality (Kersh et al. 2006). In a meta-analysis of 13 studies comparing marital satisfaction and divorce in families with and without a child with a developmental disability (e.g., Down syndrome, autism, intellectual disability), the divorce rate of parents who had a child with a disability was on average six percent higher than that of parents who did not have a child with a disability (Risdal and Singer 2004). However, when investigating only families raising children with Down syndrome, divorce rates were slightly lower than parents raising children with other congenital birth defects and those with no identified disabilities. Yet, when these parents did divorce, it was often within the first 2 years after the child's birth, a particularly stressful time (Urbano and Hodapp 2007).

Gaps in Previous Research

Although some research indicates individual stressors negatively influence marital quality and well-being, most studies investigate only wives' perceptions, and when they do investigate husbands' perceptions, it is often independent of their wives' perceptions (Bailey et al. 2007; Kersh et al. 2006; Norlin and Broberg 2013). The only study we identified that examined husband stress while raising a child with a disability did not investigate the impact husband stressors had on wife marital quality (Keller and Honig 2004). Another study, while not examining stressors specifically, found greater anxiety in parents raising children with Asperger syndrome was related not only to the parents' own adjustment, but to their partners' adjustment as well (Samios et al. 2012).

To address these deficits in the literature, we used the actor-partner interdependence model (APIM; Cook and Kenny 2005) to investigate how the characteristics of the individuals who provide the scores impact their own relationships (actor effects) and the relationships of their partner (partner effects). APIM is a design that deals with the interdependence of scores within relationships—like marriage—when the perceptions of two individuals are correlated, such that the knowledge one person provides may include information about the other person's functioning. Using this APIM design, we specifically examined actor and partner effects from husband and wife stress or uplifts with husband and wife marital quality. In other words, we examined how wife stress/uplifts not only impact her perception of marital quality (actor effect) but are related to her husband's perception of marital quality as well (partner effect). Then we did the same for husband stress/uplifts.

In addition, few studies have researched the mediating effects of parental stress and uplifts. In contrast to a moderating model, which examines interactions between variables, a mediating model attempts to describe why effects occur rather than when they occur (Quittner et al. 1990). Mediating models specify the mechanisms by which a given effect occurs, and structural equation modeling is a preferred strategy to test for mediated effects (Holmbeck 1997). In order to more fully understand the process involved in the relationships between respite care and marital quality, we tested two mediators: stress and uplifts.

Respite Care as a Resource

Respite care involves planned care for a family member with a disability to provide temporary relief or a short break to the permanent caregiver (in this study, defined as the parents). Such care could include having someone come to the family's home to tend the child during the day or to take them into the home community to engage in activities, care in a community facility, overnight respite in the family's home, care in a host family's home, or residential placement (Barron et al. 2006).

A review of 60 articles or reports published between 1980 and 2010 indicates that respite care has positive effects on the well-being of most children with disabilities

and their families (Robertson et al. 2011). Benefits were found for caregivers (e.g., reduced stress, increased relaxation and sense of renewal), children with disabilities (e.g., increased social skills, integration with typically developing children), and for siblings of children with disabilities (e.g., spend more time with parents, do activities that are otherwise impossible). Benefits were also found for family functioning (e.g., allow other family members to spend time with one another, being an 'ordinary' family). Furthermore, respite care appeared to impact parents seeking out-of-home placement for their child with disabilities.

Although many studies exist indicating positive benefits of respite care for primary caregivers, most investigate female caregivers, despite a long-standing call for more research related to fathers (Robertson et al. 2011). Also, very few investigate respite care's effects on marital quality. Robertson et al. (2011) found only three studies related to respite care that investigated marital relationships, reporting improved relationships (Stalker 1988; Stalker and Robinson 1994), or no statistical significance (Bose 1991).

A more recent study found that respite care is associated with improved marital quality of couples who have a child with ASD (Harper et al. 2013). Although much has been researched regarding the familial advantages of having a child with Down syndrome in contrast to other disabilities, there is a limited amount of research examining the relationship between both husband and wife marital quality, daily stress and uplifts, and whether respite care benefits families who have a child with Down syndrome. The purposes of this study were (a) to examine the relationship between respite care and marital quality of married couples who have a child with Down syndrome, while examining wife and husband daily stress as potential mediating variables, and (b) to assess husband and wife daily uplifts as potential mediating variables. Based on trends from the current literature, we predicted the following results:

1. Amount of respite care would be positively related to perceived marital quality for both husbands and wives.
2. Amount of respite care would be positively related to daily uplifts and negatively related with daily stress for both husbands and wives.
3. Daily uplifts would be positively related to marital quality, whereas, daily stress would be negatively related to marital quality for both husbands and wives (actor effects).
4. Partner effects from wife daily stress would be negatively related to husband marital quality, and wife daily uplifts would be positively related to husband marital quality, even when controlling for the relevant actor effects. Likewise, husband daily stress would be negatively related to wife marital quality, and husband daily uplifts would be positively related to wife marital quality, even when controlling for the relevant actor effects.
5. The relationship between respite care and marital quality would be significantly mediated by daily stress and uplifts.

Method

Participants and Settings

Of the 337 surveys submitted online, only 224 (112 wives and 112 husbands) contained useable responses. The remaining surveys were not included because they were not fully completed, did not have a matching spouse who completed the survey, or the participants had taken the survey multiple times. Therefore, this study consisted of data from 112 married couples who have a child with Down syndrome ($n = 120$; 62 male, 58 female). The participants were recruited through local and regional organizations (e.g., Friday's Kids Respite, a local respite care agency; National Down Syndrome Society), as well as through Facebook postings. Inclusion criteria were (a) the parents had a child (any age) with Down syndrome as classified by a medical diagnosis, (b) the parents were married to each other and living together, and (c) The parents were able to read English. Each couple was given a $25 gift card upon both wife and husband completion of the survey. Each partner was instructed to complete the survey independently.

Measures

Demographic Information

Each participant was asked to complete a demographic questionnaire including information about their race/ethnicity, employment, salary, education, number of children, length of marriage, annual household income, age, gender, characteristics of respite care, and medical diagnoses of the child/or children with Down syndrome. Age of parents, education, household income, race (dummy coded as 0 for Caucasian and 1 for all others), length of marriage, and number of children were used as control variables because some studies have shown that they are related to stress or marital quality (Esping-Andersen 2007; Johnson and Loscocco 2015; Miller et al. 2013).

Marital Quality

Two scales were used to measure marital quality. The Revised Dyadic Adjustment Scale (RDAS; Busby et al. 1995), which contains 14 items, was used to measure

marital adjustment using a 6-point Likert scale ranging from 0 (*always disagree*) to 5 (*always agree*). The following questions are examples: "Please indicate the extent of agreement between you and your partner on religious matters"; "How often do you and your mate 'get on each other's nerves'?" The sum of the 14 items 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 has demonstrated adequate reliability and validity, and loadings on the stated factors range from 0.74 to 0.97 (Busby et al. 1995). The Chronbach alphas for husbands and wives in this sample were 0.87 and 0.90, respectively.

The second scale, the Revised Experiences in Close Relationships Questionnaire (RECRQ; Fraley et al. 2000), measures the degree of attachment in a romantic relationship. It is comprised of two subscales, measuring anxiety and avoidance, both containing 18 items. Husbands and wives answer each item using a 7-point Likert scale which ranges from 1 (*strongly disagree*) to 7 (*strongly agree*). The following examples illustrate: "My romantic partner makes me doubt myself" and "I usually discuss my problems and concerns with my partner." Total scores from both subscales range from 18 to 126. Reported inter-item reliability is 0.93 for the anxious attachment subscale and 0.95 for the avoidant attachment subscale (Fraley et al. 2000); convergent validity with the Adult Attachment Interview (Main and Cassidy 1988) is 0.74 for the anxiety sections and 0.68 with the avoidance sections. Reliabilities in this sample for the avoidant subscale were 0.82 for fathers and 0.84 for mothers, and for the anxiety subscale were 0.85 for fathers and 0.87 for mothers.

Thus, three indicators were used to measure the latent variable, marital quality: the RDAS marital adjustment score, the RECRQ avoidant attachment score, and the RECRQ anxious attachment score.

Stress and Uplifts

The Hassles and Uplifts Scale (HUS; Lazarus and Folkman 1984) was used to indicate the two latent variables of stress and uplifts. The HUS uses a Likert scale ranging from 1 (*not at all*) to 4 (*extreme*) to rate how much each of the 53 items (including matters related to work, money, family, etc.) is a daily hassle and how much it is a daily uplift. The frequency score (range 0–53) was calculated by counting the number of items with a score greater than zero for both the hassles and uplifts. The intensity score (range 0–212) was also calculated for both the hassles and uplifts by summing the scores of all of the items. The hassles frequency score and the hassles intensity score were used as indicators of a latent variable called stress for each partner in the relationship. The uplifts frequency score and the uplifts intensity score were considered as indicators of a latent variable called uplifts for each of the partners. The HUS has demonstrated good test/retest reliability for both hassles and uplifts (Touliatos et al. 1990) and has been found to correlate with both illness and distress (DeLongis et al. 1982). Chronbach alphas in this sample for fathers and mothers on the daily hassles scale were 0.80 and 0.84, and for the uplifts scale were 0.82 and 0.86.

Respite Care

For this study, respite care was defined as planned care for the child with Down syndrome to provide temporary relief to the parents. The latent variable, respite care, had two indicators: husbands' hours of respite and wives' hours of respite. Respite care was measured by asking parents to report how much respite care they received, in hours and minutes, within a typical week. If more than one child with Down syndrome in a family was receiving respite care, we summed the hours for the second or third child, unless the parent reported that respite hours occurred at the same time as the first child. Thus, we did not double count hours if two or more children were receiving respite care during the same time.

Data Analysis

We first calculated means, standard deviations, and correlations for all study variables. A measurement model for each of the latent variables (respite care, marital quality, stress, and uplifts) was also tested. Data were analyzed with structural equation modeling using AMOS 17 (IBM Corp. 2012). An actor-partner independence model (APIM; Kenny et al. 2006) was used to estimate the effects of the amount of respite care on husband and wife relational quality (Hypothesis 1; see Figs. 1, 2). The path from amount of respite care to wife/husband daily uplifts and daily stress (Hypothesis 2) was estimated. The path joining both wife and husband daily stress and daily uplifts (Hypothesis 3) 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 4). 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 4). The indirect paths of both wife and husband daily uplifts and stresses were also calculated, with uplifts and stresses as mediating variables between respite care and marital quality (Hypothesis 5).

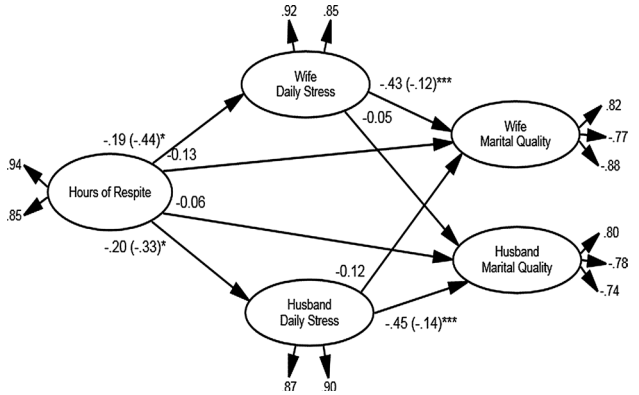

Fig. 1 Structural equation model results with respite hours predicting wife and husband marital quality with wife daily stress and husband daily stress as mediating variables. *Note 1* Unstandardized beta-coefficients appear in parentheses, with standardized beta-coefficients appearing outside parentheses. Factor loadings are noted with *arrows* pointing away from latent variables. *Note 2* Control variables included age, education, and race of husband and wife; household income; length of marriage; and number of children. However, none of these control variables were related to wife and husband daily stress nor to wife and husband marital quality, so they are not shown in the model. $*p<0.05$, $**p<0.01$, $***p<0.001$, $X^2=39.98$, $df=33$, $p=0.22$, $CFI=0.990$, $RMSEA=0.04$, $SRMR=0.05$

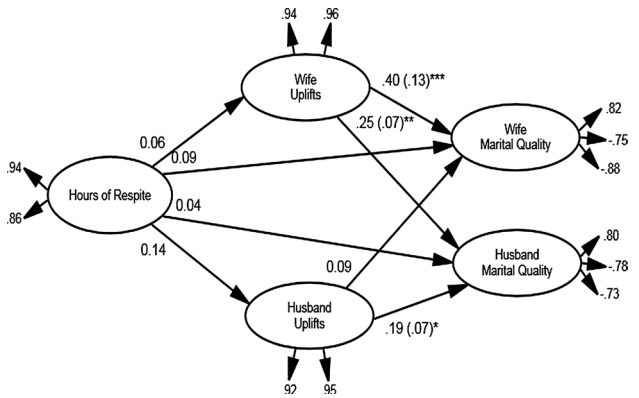

Fig. 2 Structural equation model results with respite hours predicting wife and husband marital quality with wife daily uplifts and husband daily uplifts as potential mediating variables. *Note 1* Unstandardized beta-coefficients appear in parentheses, with standardized beta-coefficients appearing outside parentheses. Factor loadings are noted with *arrows* pointing away from latent variables. *Note 2* Control variables included age, education, and race of husband and wife; household income; length of marriage; and number of children. However, none of these control variables were related to wife and husband daily stress nor to wife and husband marital quality, so they are not shown in the model. $*p<0.05$, $**p<0.01$, $***p<0.001$, $X^2=40.59$, $df=33$, $p=0.17$, $CFI=0.99$, $RMSEA=0.05$, $SRMR=0.05$

Results

Characteristics of the Participants

As shown in Table 1, the average ages for fathers and mothers were 39.06 (SD = 8.53) and 37.61 (SD = 8.39), respectively. The average length of marriage reported was 10.95 years (SD = 7.66); couples had an average of 2.65 (SD = 1.25) children. 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 was 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 %). Almost one-third of the participants (30.4 %) lived in the Rocky Mountain region of the United States; 24.1 % lived in the southern states, and 21.4 % lived in the central states. The remaining participants lived in other areas in the United States, except for 0.9 % who were living in Canada.

Of the 112 families, 57% reported receiving respite care, with 87.4% being satisfied or highly satisfied with the care they received, and only 12.6% being neutral or dissatisfied. 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). Wives' and husbands' reports of respite hours were highly correlated ($r=.83$; $p<0.001$). For these couples, 68.3 % ($n=43$) of the respite care was provided by grandparents, 34.9 % ($n=22$) by a babysitter, 22.2 % ($n=14$) by extended family, 14.3 % ($n=9$) by some other resource such as tutors, and 12.7 % ($n=8$) by an agency. Another 22 % ($n=14$) reported receiving respite care from multiple providers. Information regarding the children with Down syndrome is found in Table 2.

Correlational Data

Table 3 includes the means, standard deviations, and correlations for variables in the study. 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. RDAS scores indicated that 3.6 % of husbands and 9.8 % of wives were in the distressed marriage range (cut-off scores below 48; Busby et al. 1995). Correlations were in the expected directions. In this section, we present correlations between respite care and marital quality. See Table 3 for other correlations.

Both indicators of stress (severity and frequency) as reported by husbands and wives were significantly related to the three indicators of marital quality reported by both husbands and wives. Also, many of the uplifts indicators (intensity and frequency) were related to marital quality in the expected direction. Wife respite hours was correlated with indicators of marital quality (i.e., wife marital adjustment, husband and wife avoidant attachment). Husband respite hours was not related to any marital quality indicators.

Measurement and Structural Models

Figure 1 shows the factor loadings for each measured variable on its 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 this model indicated that, as hypothesized, it was a good fit to the data based on Kline's (2010) recommendations. The Chi square was insignificant ($\chi^2 = 39.98$, $df = 33$, $p = 0.22$); the Comparative Fit Index (*CFI*) was well above 0.95 (*CFI* 0.990); the Root Mean Square Error of Approximation (*RMSEA*) was <0.05 (*RMSEA* = 0.04); and the Standardized Root Mean Square Residual (*SRMR*) was <0.08 (*SRMR* 0.05). The overall R^2 was 0.30 for husband marital quality and 0.21 for wife marital quality.

Figure 2 shows the results for the model with husband and wife uplifts as potential mediators. Again the overall fit indices showed that the hypothesized model was a good fit to the actual data, with a *CFI* of 0.99, an *RMSEA* of 0.05, and an *SRMR* of 0.05. The Chi square was insignificant ($\chi^2 = 40.59$, $df = 33$, $p = 0.17$). The overall R^2 for this second model was 0.17 for husbands and 0.14 for wives.

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; however, this relationship was not statistically significant (Figs. 1, 2). Therefore, Hypothesis 1 was not supported.

Hypothesis 2 stated that there would be a positive relationship between amount of respite care and daily uplifts, as well as a negative relationship between respite care and daily stress. The relationship between the hours of respite care and husbands' and wives' daily uplifts was not significant. However, as seen in Fig. 1, there was a significant negative relationship between amount of respite care and the daily stress of wives ($\beta = -0.19$, $p < 0.05$) and husbands ($\beta = -0.20$, $p < 0.05$). Therefore, Hypothesis 2 was partially supported for both husbands and wives.

Hypothesis 3 stated that daily stress would be negatively related and daily uplifts would be positively related with marital quality for both husbands and wives. Actor effects were found for the relationship between stress and marital quality for wives ($\beta = -0.43$, $p < 0.001$) and husbands ($\beta = -0.45$, $p < 0.001$; see Fig. 1). As seen in Fig. 2, husband uplifts were positively related to husband marital quality ($\beta = 0.19$, $p < 0.05$), and wife uplifts were related to wife marital quality ($\beta = 0.40$, $p < 0.001$). Therefore, Hypothesis 3 was confirmed for both wives and husbands.

Hypothesis 4 was related to partner effects: how one individual's daily uplifts or stress related to the partner's report of marital quality. Neither wives' nor husbands' daily stressors were significantly related with their partner's marital quality (Fig. 1). Figure 2 shows that husband daily uplifts were not significantly related to wife marital quality. However, wife daily uplifts were positively related to husband marital quality ($\beta = 0.25$, $p < .01$). Therefore, Hypothesis 4 was only partially supported.

Hypothesis 5 stated that the relationship between respite care and marital quality would 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 Fig. 1 evidenced significant mediation effects and whether mediation for the four indirect paths in Fig. 2 was significant. The standardized indirect effect of 0.08 showed that wife daily stress significantly mediated the path from hours of respite to wife marital quality (95% CI 0.021–0.234, $p < .01$), and husband daily stress

Table 1 Demographic characteristics of husbands and wives (N = 112 husbands, 112 wives) of children with Down syndrome (DS)

Variables	Husbands	Wives
	Mean (SD)	
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/ethnicity		
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%
Geographic location		
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 and their siblings in 112 families

	Males		Females		Combined	
	Down syndrome	No diagnosis	Down syndrome	No diagnosis	Down syndrome	No diagnosis
Birth order of child						
1st	23	34	21	30	44	64
2nd	14	35	20	21	34	56
3rd	12	20	11	14	23	34
4th	10	5	2	8	12	13
5th	1	3	2	1	3	4
6th	1	0	1	0	2	0
7th	1	0	1	0	2	0
8th	0	1	0	0	0	1
Total	62	98	58	74	120	172
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)

significantly mediated the paths from hours of respite to husband marital quality ($\beta = 0.09$, 95% CI 0.019–0.256, $p < .01$). Mediation was not statistically significant for the other two indirect paths in Fig. 1 or for any of the four indirect paths in Fig. 2. Hypothesis 5 was partially supported by daily stress mediating the relationship between hours of respite and marital quality for husbands and wives. Because a proportion of the sample reported receiving no respite care, we decided to include a dichotomous variable for respite with those reporting no respite care being coded as 1 and those receiving care coded as 2. This allowed us to keep all the variation in respite care hours and still control with a categorical variable that included the dimension of many respondents not receiving respite care. The statistically significant paths stayed the same with only minor variations among the coefficients. Because there was no difference in the findings, we do not report that model here.

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 Down syndrome. Interestingly, the marital quality of our sample was high, with only approximately 4% of husbands and 10% of wives reporting distressed marriages. This is in contrast to research of parents with autism spectrum disorders, where approximately 15% of husbands and 17% of wives reported distressed marriages (Harper et al. 2013). A short discussion the support for our hypotheses follows.

Relationship Between Respite Care and Marital Quality

Respite care was not directly related to marital quality for husbands or wives; instead, it was indirectly related through husband and wife stress. The lack of direct relationships between respite care and marital quality is similar to that found by Bose (1991), but contradicts the relationships found by Stalker (1988) and Stalker and Robinson (1994). However, these three studies included participants raising children with various disabilities, whereas our study was focused on Down syndrome.

Relationship Between Respite Care and Stress

Results indicated that respite care was negatively related to both wife and husband stress. These results are consistent with other findings that increased respite care lowers stress for both fathers and mothers (Mullins et al. 2002). However, children in that study, whose developmental disabilities included cerebral palsy, Down syndrome, and intellectual disabilities, were admitted to inpatient respite care for 24 h per day for 3–7 days. While stress was significantly lower after the brief respite care, the parents' stress had returned to high levels after 6 months. In contrast, the respite care provided to participants in the present study occurred more consistently (e.g., weekly, daily) and was typically provided by grandparents and babysitters. Results imply that respite care provided on a regular basis can significantly decrease levels of stress for both husbands and wives and in turn increase marital quality.

Relationship Between Stress, Uplifts, and Marital Quality

When wives experienced stress, they perceived their marriage to have lower quality; similarly, when husbands experienced stress, they had lower quality marriages. However, there were no significant relationships between wife daily stress and her partner's marital quality, nor were there

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. W respite hours	1.0													
2. H respite hours	0.83***	1.0												
3. W stress severity	−0.20*	−0.18*	1.0											
4. W stress frequency	−0.14	−0.17*	0.87***	1.0										
5. H stress severity	−0.17*	−0.19*	0.63***	0.54***	1.0									
6. H stress frequency	−0.19*	−0.15	0.57***	0.56***	0.87***	1.0								
7. W uplifts intensity	0.04	−0.10	−0.36***	−0.29***	−0.24**	−0.21**	1.0							
8. W uplifts frequency	0.07	−0.05	−0.31***	−0.13	−0.21**	−0.14	0.90***	1.0						
9. H uplifts intensity	0.13	0.10	−0.29***	−0.30***	−0.18*	−0.19*	0.61***	0.55***	1.0					
10. H uplifts frequency	0.15*	0.16*	−0.22**	−0.19*	−0.15*	0.01	0.49***	0.51***	0.87***	1.0				
11. W marital adjustment	0.15*	0.09	−0.43***	−0.37***	−0.34***	−0.35***	0.40***	0.36***	0.20*	0.15	1.0			
12. W anxious attachment	−0.12	−0.11	0.36***	0.38***	0.27***	0.28***	−0.21**	−0.14	−0.04	−0.01	−0.58***	1.0		
13. W avoid attachment	−0.15*	−0.06	0.32***	0.28***	0.22**	0.24**	−0.28***	−0.24**	−0.11	−0.05	−0.73***	0.67***	1.0	
14. H marital adjustment	0.02	0.07	−0.33***	−0.40***	−0.46***	−0.47***	0.40***	0.33***	0.34***	0.27***	0.67***	−0.50***	−0.56***	1.0
15. H anxious attachment	−0.06	−0.07	0.31***	0.38***	0.37***	0.35***	−0.18*	−0.13	−0.18*	−0.17*	−0.54***	0.52***	0.59***	−0.58***
16. H avoid attachment	−0.04***	−0.05	0.19*	0.30***	0.24**	0.23**	−0.25**	−0.12	−0.27***	−0.27***	−0.48***	0.48***	0.47***	−0.60***
17. H age	−0.08	−0.09	−0.04	−0.05	−0.01	0.00	0.08	0.05	0.09	−0.08	0.05	0.06	0.09	−0.04
18. W age	−0.08	−0.08	0.02	0.01	−0.01	−0.00	0.06	0.08	−0.06	−0.10	0.12	0.07	0.08	−0.03
19. H education	0.07	0.11	−0.13	0.02	−0.17*	−0.01	0.09	0.17*	0.09	0.06	0.20**	−0.10	−0.12	0.05
20. W education	0.14	0.15*	0.05	0.12	−0.01	0.04	0.08	0.06	−0.06	−0.13	0.14	0.02	0.04	−0.17*
21. Household income	0.20*	0.17*	−0.20**	−0.07	−0.22**	−0.14	−0.17*	0.09	−0.03	−0.05	0.01	−0.06	0.01	−0.05
22. H race	−0.10	−0.04	0.03	0.01	0.05	0.04	0.10	0.12	−0.14	−0.15	0.00	−0.05	0.06	−0.07
23. W race	−0.07	−0.01	−0.05	−0.07	−0.03	−0.06	−0.14	−0.05	−0.03	−0.06	0.07	−0.02	−0.03	0.12
24. Length of marriage	−0.10	−0.11	−0.08	−0.04	0.07	0.10	0.22**	−01	0.02	0.01	0.05	0.03	0.06	−0.07
25. # of children	−0.18*	−0.13	0.10	0.08	0.15*	0.17*	0.15	0.12	0.10	−0.04	0.07	0.04	0.05	0.05
M	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
S.D	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

	15	16	17	18	19	20	21	22	23	24	25
15. H anxious attachment	1.0										
16. H avoid attachment	0.60***										
17. H age	0.01	0.08	1.0								
18. W age	−0.04	0.09	0.92***	1.0							
19. H education	0.09	−0.03	0.21**	0.16*	1.0						
20. W education	−0.05	0.11	0.16*	0.20*	0.51***	1.0					

Table 3 (continued)

	15	16	17	18	19	20	21	22	23	24	25
21. Household income	−0.04	0.13	0.22**	0.33***	0.45***	0.39***	1.0				
22. H race	0.04	−0.09	0.06	−0.12	−0.14	−0.16*	−0.09	1.0			
23. W race	0.03	−0.07	0.05	−0.05	−0.07	−0.18*	0.08	0.31***	1.0		
24. Length of marriage	0.02	0.15	0.68***	0.61***	0.27***	0.04	0.33***	−0.10	−0.01	1.0	
25. # of children	−0.03	−0.06	0.10	0.09	0.08	−0.06	0.13	−0.21**	−0.06	0.35***	1.0
M	44.77	43.07	39.06	37.61	N/A	N/A	$64,387	N/A	N/A	10.89	2.65
S.D	22.52	19.57	8.53	8.39	N/A	N/A	$25,278	N/A	N/A	7.74	1.25

N/A means that the data were categorical (e.g., education, race) so reporting a mean and standard deviation would not convey meaningful information

W wife, *H* husband

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$

relationships between husband daily stress and his partner's marital quality.

Wife uplifts were positively correlated with both wife and husband marital quality. The more perceived uplifts the wife experienced, the better marital quality both reported. Similar to the findings of Robertson et al. (2011), this study concluded that respite care can provide time to participate in uplifting events for parents who have a child with a disability. These uplifts correlate with positive mental health outcomes and better ability to cope with stressful life events.

Although uplifts were positively correlated with marital quality in the current study, respite care was not correlated with uplifts 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, with both husbands and wives reporting a high number of items as uplifts. The intensity of their uplifts was also fairly high. Thus the number of hours of respite care may not have been sufficient to impact the uplift scores. Second, the activities the parents performed while the child was receiving respite care may not have impacted uplifts: for example, running errands or completing chores may not have been uplifting.

Mediating Roles of Stress and Uplifts

Previous research indicated that families with a child with Down syndrome reported higher levels of stress and lower levels of adaptability and coping skills compared to families with typically developing children (Hodapp and Urbano 2007). Also, Norlin and Broberg (2013) suggested that having a child with a disability may decrease couples' ability to support and collaborate with each other. A notable finding in the current study shows that stress mediated the relationship between the amount of respite care and marital quality. Thus, couples with higher levels of respite care perceived lower levels of stress, which was related to elevated levels of marital quality. Respite care may allow couples the time they need to spend together to enhance their marital relationship, possibly lowering stress and thus increasing marital quality.

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 and Whiteley 2012). The current study did not find uplifts to be a mediator between respite care and marital quality. But perhaps parents in our sample had sources of uplifts that were not measured which impacted their marital quality. Additionally, parents who perceive more uplifts in their lives might be less likely to seek respite care services than parents who experience fewer uplifts. Additional studies may provide more insight into these relationships.

Limitations

This study had several limitations. First, the sample was not representative or random: The participants were volunteers, most were Caucasian, and were mainly recruited from local and regional organizations. Non-Caucasian families and families who do not have access to support organizations may be different in some ways from families in our sample. Also, since there are no accepted, standardized measures of respite care, self-reporting may have resulted in certain biases. Finally, this study was cross-sectional, so no inferences can be made about causation among the variables. Because the 53 items for the HUS are the same, and the participants were asked to consider each item as both a hassle and uplift, there is a possibility that there is shared variance between the measures. We did not include both uplifts and hassles in the same statistical model, but the results do not clarify how much shared variance there might be.

Implications for Further Research

The findings of this study raise several questions, such as the following: Why do some families receive respite care and others do not? What activities do parents engage in to maximize the benefit of receiving respite care? What family characteristics or resources predict marital quality in families raising children with Down syndrome? Why has respite care been shown to directly impact marital quality in parents who have a child with ASD, but not those with a child with Down syndrome (see Harper et al. 2013)? Studies are needed to compare these issues in families raising children with Down syndrome and other families to better understand their unique needs.

The current study found that most respite care was provided by grandparents, with very little provided by community agencies. Parents may be unaware of respite care provided by community agencies, they may not know how to access such care, they may not be able to afford respite care, or they may be satisfied with their current caregiving situation and see no need to access outside care. Further study regarding knowledge and access to care is critical, especially for parents who do not have extended family nearby to provide respite care.

Implications for Policymakers and Practitioners

The findings of this study are relevant for policymakers. Many parents who need formal respite care for their child with Down syndrome find that it is not available, too expensive, or in such high demand that it is difficult to acquire. Respite care providers, who are often paid minimum wage salaries, have a high turn-over rate that makes it even more difficult for families to access quality care. The financial demand forces many to leave their employment, take out loans, or tap into savings in order to provide in-home care for their children with disabilities because affordable quality care is not available to them.

Informal respite care, generally provided by family members and babysitters, is often restricted due to complex family issues and insufficient training. The findings of this study provide some support for policymakers who desire to make respite care more affordable and accessible to families raising children with Down syndrome. A coordinated national strategy is warranted to bring together government officials, community leaders, service providers, and family members to provide recommendations related to supporting both family caregivers and formal respite care providers [e.g., H.R. 3099: Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act].

To address the needs of families who do not access formal respite care, laws could be enacted to provide tax credits for those who provide in-home care to family members with chronic conditions or disabilities. Having such support could offset some of the expenses families experience such as creating accessible home spaces, adapting transportation, and hiring in-home respite care, thus allowing the child with disabilities to remain in the family home and community.

When family members take time away from work to care for their loved ones with disabilities, they jeopardize their Social Security benefits. Legislation such as the Social Security Caregiver Credit Act (S.2721: Social Security Caregiver Credit Act of 2016) would ensure that these citizens do not lose their retirement benefits when they care for their family members with disabilities for at least 80 h per month for up to 5 years.

There are many implications from these findings for practitioners who work with families who have children with Down syndrome. Practitioners, especially those who work in school settings, should be aware of and responsive to the challenges facing parents raising children with Down syndrome. Respite care services should be discussed at meetings involving the child's Individual and Family Service Plan (IFSP) or Individualized Education Program (IEP). A member of the IFSP or IEP team should take responsibility to inform and guide the family in accessing such care, particularly parents of infants recently diagnosed with Down syndrome, who may experience difficulty navigating, locating, and coordinating a fragmented maze of services. Having respite care services coordinated as part of the family-centered service planning process may likely reduce this care being "offered as a 'stand alone' service that is unconnected to other support services" (Mannan et al. 2011, p. 49).

Although respite care services are not typically listed in a student's IEP as a service provided by the school, school personnel can offer respite care for school events such as

parent-teacher conferences, back-to-school night, and particularly for meetings where the parents' attendance is required, such as IEP, transition, or behavior intervention plan meetings. Having access to quality respite care may increase parents' ability to attend school meetings and events.

Non-profit groups, community organizations, and university students can work with local schools to provide respite care to families in need. Having a variety of trained, nurturing, and qualified formal and informal respite care providers is critical for parents to feel comfortable sharing the responsibility of caring for their child with Down syndrome.

Conclusion

In this sample of 112 married couples raising children with Down syndrome, the amount of respite care was not directly related to marital quality, but the relationship between respite care and marital quality was mediated by stress. This study contributes to the literature by adding the perspective of fathers, and by using APIM to investigate the interdependence of scores of husbands and wives. Because respite care helps reduce stress, and lower levels of stress increases marital quality, appropriate points of intervention for practitioners would include increasing the provision of respite care and helping families reduce their daily stress levels.

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Author Contributions Tina Dyches coordinated and supervised all aspects of the study, including the research design and methods. She designed the data collection process, assisted in data collection/analysis, and assisted in writing/revising all sections of the manuscript from initiation to revision. Michelle Norton collected the data, assisted with analyzing the data, and assisted in writing all sections of the manuscript. James Harper was lead researcher in conducting the data analysis, and in writing the results and measures sections. He responded to reviewers' concerns and questions about those parts. Susanne Olsen Roper contributed to the instrument selection and development, and to the writing and editing of the entire manuscript and also to the revision process. She also provided statistical analysis assistance. Paul Caldarella was a member of the research planning committee and contributed to the study by providing recommendations to enhance the literature review, methodology, and results sections, as well as by reading and editing the final completed manuscript.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflicts of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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