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Respite Care, Stress, Uplifts, and Depression in Single Mothers of Children with Autism Spectrum Disorders

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Respite Care, Stress, Uplifts, and Depression in Single Mothers of
Children with Autism Spectrum Disorders

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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, Stress, Uplifts, and Depression in Single Mothers of Children with Autism Spectrum Disorders

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Single mothers of children with autism spectrum disorders (ASD) are likely to experience high levels of stress and be at risk for depression. However, respite care can reduce parenting stress and lower psychological distress in parents of children with disabilities. This study focused on single mothers of children with ASD and their reports of stress relative to respite care received. One hundred and twenty-two single mothers completed the Respite Care Instrument, Center for Epidemiological Studies Depression Scale, Hassles and Uplifts Scale, and Caregiver Burden Instrument. Results were mixed. Respite care was positively related to daily uplifts, but not significantly related to depression or stress. Uplifts mediated the relationship between respite care and depression, but stress did not mediate the relationship between respite care and depression, indicating uplifts were a process through which respite care had an indirect effect on depression. More than half (59.8%; $n = 73$) of mothers accessed respite care, most (41.0%; $n = 30$) being provided by a combination of sources: grandparents, extended family member, babysitter, community agency, or other. Seventy-seven percent of mothers ($n = 94$) were at risk for clinical depression. Findings provide evidence that single mothers of children with ASD are likely to experience depressive symptoms, access multiple sources of respite care, and be less likely to report depressive symptoms when they (a) receive respite care, and (b) report high amounts of daily uplifts. Therefore, it is important respite care be accessible and provided to single mothers of children with ASD. Recommendations for policy makers, school personnel, and research are offered.

Keywords: autism, caregivers, depression, mothers, one-parent family, single mothers, respite care

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DESCRIPTION OF THESIS STRUCTURE

This thesis, *Respite Care, Stress, Uplifts, and Depression in Single Mothers of Children with Autism Spectrum Disorders*, is written in a format combining the requirements for a traditional thesis and journal publication. The beginning of the thesis includes requirements for a traditional thesis for submission to the university. The overall report is in journal article format and will be suitable to submit immediately to education journals for publication.

The literature review can be found in Appendix A. Consent forms and recruitment materials can be found in Appendix B. The instruments used to gather data can be found in Appendix C.

Two reference lists are contained in this thesis. The first includes references used in the journal article portion of the thesis; the other includes references cited in Appendix A, entitled “Review of the Literature.”

Background

Single parenting is becoming more common than traditional families (consisting of a mother, father, and children) over the past 20 years (American Psychological Association, n.d.). In fact, according to the U. S. Census Bureau (Vespa, Lewis, & Kreider, 2013), 27% of the 39 million family groups studied were made up of mother-only family groups, compared to 67% comprised of married couple homes. Single-parent families face numerous obstacles; for example, children in mother-only homes are four times as likely to live in poverty than children living with two parents. Specifically, according to the U.S. Census Bureau (Vespa, et al., 2013) approximately 36% of children from single-mother homes lived in poverty, while only 9% of children from married-parent homes lived in poverty. After reviewing the data from the Fragile Families and Child Wellbeing Study (FFCW), Osborne, Berger, and Magnuson (2012) found mothers who exited cohabiting or marital relationships within the first five years of the child's birth were more likely to experience increased material hardships, depression, and parenting stress with decreased perceived social support.

Single mothers typically have fewer resources than married mothers; so they may require more help coping and more access to resources due to the stressors they face. For example, single mothers report more symptoms of depression than married mothers (Atkins, 2010). In addition, in a study of 2,921 single and married mothers, Cairney, Boyle, Offord, and Racine (2003) found single mothers were twice as likely in the previous year to be depressed than married mothers; 40% of single mothers reported their depressive symptoms were due to high levels of stress and low levels of social support.

Both single-parent and married-parent families raising children with disabilities experience different challenges than families raising typically developing children (TDC; King,

2006). For example, in a qualitative study of parents raising children with Down syndrome and autism, King (2006) found recurring themes including the life-changing experience of having a child with a disability and coping with lost dreams for that child.

Autism spectrum disorder (ASD) is one of many developmental disabilities that impact family functioning (Davis & Carter, 2008). ASD is currently viewed as an epidemic in the United States and considered an important public health concern, with estimates of 1 in 68 children (or 14.7 per 1,000 8-year-olds) being identified as having ASD (Centers for Disease Control and Prevention, 2014, 27 March). This increasing prevalence, up from 1 in 88 children reported in 2012, indicates an increasing number of families raising these children. Many families are negatively affected emotionally (Ekas & Whitman, 2010), socially, and financially (Lee, Harrington, Louie, & Newschaffer, 2008; Montes & Halterman, 2008) by the diagnosis.

Raising children with ASD presents a particular challenge to parents. For example, researchers administered the *Parenting Stress Index* (PSI) to 104 mothers of children with autism and 342 mothers of typically developing children (TDC) and found mothers of children with autism had significantly higher levels of stress than mothers of TDC (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009). The PSI assesses whether parental stress can be attributed to child-related factors or to parent-related factors, and the scores indicated mothers of children with autism had significantly higher stress levels in both the Child Domain and the Parent Domain. Parents who score at or above the 90th percentile in the total PSI score are experiencing significant levels of stress (Abidin, 1995). The Child Domain scale of mothers of TDC fell in the 40th percentile, while mothers of children with autism fell in the 99th percentile. Parent Domain percentiles were the 75th percentile for parents of children with autism and 45th percentile for parents of TDC.

Several factors may increase stress, including perceived social support, the child's behaviors, maternal depression, and caregiver burden. For example, social support was associated with greater mental health related quality of life (MHRQOL) for caregivers of children with ASD (Khanna et al., 2011), and increased social support reduced familial stress for families with children with ASD (Dale, Jahoda, & Knott, 2006). Likewise, Siman-Tov (2011) found social support decreased stress for 176 parents of children with ASD, because it gave parents more of a sense of control in their lives. Social support also was a mediating variable in relation to the impact of behavioral problems and its link to MHRQOL in these families (Khanna et al., 2011).

A child's challenging behavior is related to increased stress. For example, Baker, Blacher, Crnic, and Edelbrock (2002); Baker et al. (2003); and Baker, Blacher, and Olsson (2005) found children with developmental disabilities exhibited more problem behaviors than TDC. Behavior problems also were associated with (Benson & Kersh, 2011; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006) and explained levels of parenting stress (Baker et al., 2002, 2003; Lecavalier, Leone, & Wiltz, 2006). These findings are congruent when comparing mothers of children with ASD and mothers of children with Down syndrome and other intellectual disabilities. Additionally, Griffith, Hastings, Nash, and Hill (2010) discovered mothers of children with autism reported more problematic behaviors in their children and higher stress levels than mothers of children with Down syndrome and mixed-etiology intellectual disabilities.

Maternal depression is also related to increased stress. Specifically, Carter, Martínez-Pedraza, and Gray (2009) found low social supports and coping styles were associated with the severity of depression in mothers of children with ASD, and many of these mothers are at risk for clinical depression. For example, Smith, Seltzer, Tager-Flusberg, Greenberg, and Carter (2008)

studied a group of 153 mothers of toddlers with ASD and 201 mothers of adolescents with ASD and found over one third of both groups of mothers were at high risk for clinical depression based on scores on the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). In fact, mothers of toddlers with ASD and mothers of adolescents with ASD scored similarly on the scale, perhaps indicating length of time since diagnosis did not reduce the depressive symptoms of the mother.

Finally, caregiver burden affects stress. Caregiver burden is defined as “a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual” (Kim, Chang, Rose, & Kim, 2012, p. 846). According to Lee et al. (2008), families of children with ASD reported greater childcare burden than families of children with attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD) and those with TDC. In addition, these parents were more likely to quit their jobs in order to take care of their children when compared to parents of both children with ADD/ADHD and TDC.

With heightened levels of stress due to single parenting a child with ASD, perhaps a break from parenting responsibilities could reduce these parents’ stress. Stress levels of parents of children with disabilities were reduced after receiving respite care (Cowen & Reed, 2002). Respite care refers to temporary care provided for individuals with disabilities with the primary goal of providing relief to the individual’s primary caregiver (Mullins, Aniol, Boyd, Page, & Chaney, 2002; Strunk, 2010).

Over the past decade respite care has been studied in relation to parental mental health. For example, Cowen and Reed (2002) found giving parents of children with disabilities a break from parenting demands significantly reduced their stress levels. Mullins et al. (2002) also found respite care was associated with lower psychological distress in parents of children with

developmental disabilities. While research indicates respite care can be beneficial to married parents of children with ASD (Harper, Dyches, Harper, Roper, & South, 2013), there is little to no research quantifying the amount of respite care children with ASD are receiving and how that affects single mothers' perceptions of depression, daily uplifts and hassles, caregiver burden, and the relationships between these factors.

Problem Statement

Single mothers of children with ASD do not appear to be represented in research literature discussing parenting children with ASD. Because single mother households comprise an increasing proportion of the population in the U.S., it is important to study and understand the stresses and problems these mothers face. Doing so may increase the ability of healthcare professionals, psychologists, special educators, and other professionals to understand and help single mothers of children with ASD. Therefore, this study was designed to determine how respite care is related to depression, with stress and uplifts as mediators through which respite care is related to depression, in single mothers of children with ASD. Figure 1 shows the measurement and structural model for this study.

Statement of Purpose

The current project is an extension study of Harper et al. (2013)'s study, "Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders," which examined married parents' experiences of raising children with ASD and focused on the relationships among respite care, marital quality, and stress. The purpose of this study is twofold: (a) to investigate the perceptions of single mothers of children with ASD in regard to their daily hassles and uplifts, caregiver burden, depression, and respite care, and (b) to examine the relationships between respite care and depression with stress and uplifts as mediators.

Research Questions

This study addressed three research questions:

1. What is the relationship between single mothers' reports of the amount of respite care received and their perceptions of uplifts?
2. What is the relationship between single mothers' reports of the amount of respite care received and their perceptions of stress as measured by caregiver burden and daily hassles?
3. What is the relationship between single mothers' reports of the amount of respite care received and their perceptions of depressive symptoms?

Hypotheses

Based upon trends from the current literature, the following was predicted:

1. Amount of respite care would be negatively associated with depressive symptoms of single mothers of children with ASD.
2. Amount of respite care would be negatively associated with stress (as measured by daily hassles and caregiver burden) for single mothers of children with ASD.
3. Amount of respite care would be positively associated with daily uplifts for single mothers of children with ASD.
4. The relationship between respite care and depression would be significantly mediated by stress as measured by daily hassles and caregiver burden.
5. The relationship between respite care and depression would be significantly mediated by daily uplifts.

Method

The purpose of this study was to examine the relationships between respite care and depressive symptoms with stress (as measured by daily hassles and caregiver burden) and uplifts as potential mediating variables among single mothers of at least one child with ASD. After receiving approval from the university's Institutional Review Board (IRB), participants were recruited to complete surveys regarding the variables of interest.

Participants and Settings

The sample was comprised of 122 non-cohabiting single mothers of children diagnosed by a medical professional or classified by the child's school as having ASD: Autism, Asperger Syndrome, or Pervasive Developmental Disorder – Not Otherwise Specified. The mothers were recruited through electronic newsletters, distribution lists, and organizations related to ASD (e.g., Autism Speaks).

These organizations were invited to advertise this study on their websites and through their social networking outlets. If they agreed to advertise the study, a link was made available through their correspondence (e.g., electronic newsletter, website), which took potential participants to the consent form and questionnaire or a link to request a hard copy of the questionnaire. A Facebook page was also created in order to recruit single mothers via social networking. Here, there was an option available for participants to complete the questionnaire in a paper format. Participants were given a phone number and an e-mail address in order to request the paper copy. A copy of the recruitment information and consent forms can be found in Appendix B.

The 122 single mothers were between the ages of 22 and 55. They were single—never married (23.8%; $n = 29$), or divorced, widowed, or separated (76.2%; $n = 93$). Each single

mother had at least one child with ASD living in the home, no matter the age. The majority (71.3%; $n = 87$) identified themselves as non-Hispanic White and a little over half were living in the West region (53.3%; $n = 65$) of the United States. All single mothers graduated from high school and many (43.5%; $n = 53$) received a bachelor's degree. For 49% of participants, annual income was less than \$25,000 ($n = 60$).

Twenty-one mothers (17.2%) reported having more than one child with ASD; 18 (14.7%) reported having two children with ASD, and three mothers (2.4%) reported having three children with ASD. The total number of children with ASD was 146; however, important demographic data from four of those reported children were missing (e.g., gender, age, or medical diagnosis) and thus they were not included in the study. Therefore, the total number of reported children with ASD is 142.

According to mothers' reports, the mean number of children in the family, including TDC, was 2.14 ($SD = 1.09$). Of the 142 children (30 females, 112 males) with ASD, 84.5% ($n = 120$) had medical diagnoses of ASD (e.g., Autism, Asperger, Pervasive Developmental Disorder-Not Otherwise Specified), and the remaining 15.5% ($n = 22$) were categorized as having an unconfirmed source of ASD diagnosis.

Measures

Four measures were used in this study, including the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977), the Caregiver Burden Instrument (Robinson, 1983), the Hassles and Uplifts Scale (HUS; Lazarus & Folkman, 1984), and the Respite Care Instrument (see Appendix C). These instruments are described in the following sections. The latent variable, stress, was created using three indicators: the intensity scores and frequency scores from the daily hassles subscale of the HUS and the amount of caregiver burden from the

Caregiver Burden Instrument. The latent variable called uplifts was created with two indicators: the intensity scores and frequency scores from the daily uplifts subscale of the HUS.

Depression. Depression was assessed with the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). The CES-D is a 20-item self-report scale of depressive symptoms (sum range = 0–60); scores of 16 or above are considered at risk for clinical depression. Single mothers indicated how often they experienced the symptoms during the past week using a four-point Likert scale from *Rarely or none of the time* to *Most or all of the time*. The scale used in this study ranges from 1–4; however, during analysis the scores were changed to 0–3 to be consistent with CES-D scoring and cutoff. Higher scores indicate higher likelihood of a major depressive episode. Sample statements include, “I had trouble keeping my mind on what I was doing,” “I felt that I could not shake off the blues even with help from my family and friends,” “I was happy,” and “I felt hopeful about the future.” The CES-D has high internal consistency (alphas = .85 to .90) in both psychiatric and community populations and moderate test-retest reliability (alphas = .40 and above; Radloff, 1977). The reliability for the current sample was alpha = .82. The sum of the items answered was used in the model.

Caregiver burden. The Caregiver Burden Instrument, adapted by Robinson (1983) from the Caregiver Strain Index (CSI), measured major factors influencing caregiver burden and identified caregivers at risk for burden. In the current study, the sum of the scale was one indicator of the latent variable, stress. The Caregiver Strain Index assesses the caregiver burden of someone caring for an older adult patient, but it has been adapted for the purposes of this and other studies to work with the caregiver burden of children’s parents. Reliability for this measure is acceptable for samples of families of children with disabilities and diabetes, ranging from Cronbach’s alpha .86 to .88 (Jubber, Olsen Roper, Yorgason Poulsen, & Mandleco, 2013; Platt,

Roper, Mandleco, & Freeborn, in press). The reliability for the current study is .92. This measure consists of 20 items related to burdens (13 items) or beneficial aspects (seven items) of caring for children (e.g., “feeling that my children provide stimulation and learning for me,” “feeling that my children teach me wonderful and worthwhile things,” “feeling that my time is not my own,” “feeling physically or emotionally drained by caring for my children,” “feeling financial strain involved in caring for my children”). Mothers were asked to rate themselves on how frequently they experienced those feelings (1 = rarely; 4 = constantly; sum range = 20–80). The factor loading for the measure on the latent variable stress was .85.

Daily hassles and uplifts. The Hassles and Uplifts Scale (HUS; Lazarus & Folkman, 1984) contains two subscales, hassles and uplifts, and includes 53 descriptions of daily events such as work, children, relationships, and money (e.g., “nature of your work,” “your work load,” “your children,” “time spent with family,” “social commitments,” “enough money for necessities such as food, clothing, housing, health care, taxes, insurance,” “enough money for education”). Participants indicated how much of a daily hassle (annoyance or bother) and how much of a daily uplift (satisfaction, gladness) they experienced from each item, using a Likert scale from 0 (Not at all) to 4 (Extreme). Item frequency is determined by counting the number of items with a score greater than zero (range 0–53) while intensity is determined by summing the scores of all items (range 0–212). The HUS correlates with illness and distress and has good test-retest reliability for hassles and uplifts (Touliatos, Perlmutter, & Straus, 1990). The reliability for the current study was $\alpha = .96$ for hassles, and $\alpha = .95$ for uplifts. The stress and uplifts variables were based on both frequency, shown in the sum of items that have a score greater than zero (range 0–53), and intensity, shown in the sum of all of the scores (range 0–212). An additional item, “dating partner,” was added to this study as a single mother may be dating. This

addition makes the sum of items range from 0–54 and intensity or the sum of all scores range from 0–216. The intensity and frequency scores from the hassles subscale were used as indicators, along with the Caregiver Burden Instrument scores discussed above, of the latent variable stress. The intensity and frequency scores from the uplifts subscale were used as two indicators of the other latent variable, uplifts. The factor loadings of hassles intensity and hassles frequency were .96 and .91, respectively. The factor loadings of uplifts intensity and uplifts frequency were .95 and .94.

Respite care. The Respite Care Instrument was developed by Harper et al. (2013) to measure several variables (e.g., amount, respite care providers, satisfaction of care) related to receiving respite care. In the Respite Care Instrument, respite care refers to “planned care for the child with ASD to provide relief to the permanent caregiver.” Aspects of respite care were measured with four questions. The first question asked mothers to indicate if they received respite care from (a) grandparents, (b) extended family member, (c) babysitter, (d) community agency, and/or (e) other (indicate). If the mother responded that any of these sources provided respite care, the second question asked her to indicate the amount of time the source provided respite care in hours and minutes from Sunday to Saturday in a typical week during the school year. The amounts given for each source were combined to determine the total amount of respite care provided. We controlled for mothers who have more than one child receiving respite care by only adding hours if the children’s respite care time did not overlap. If one or more children were receiving respite care at the same time, those hours were counted only once rather than adding additional hours for shared respite; however, if the children were receiving respite care at different times, more hours were added to the final count. The third question asked mothers to

indicate their levels of satisfaction with respite care provided by each source. Finally, mothers indicated how they usually spend their time while their children receive respite care.

Demographic questionnaire. Demographic information was collected using a questionnaire including questions asking about age, gender, marital status, annual household income, education level, race, amount of child support received, number of children, and age, gender, and medical diagnoses/educational classification of the child or children with ASD. These variables were used as control variables in the analysis.

Procedures

After receiving IRB approval to conduct the research, potential participant mothers of children with ASD were recruited and directed on Facebook or via e-mail to click a link to access the online questionnaire created with Qualtrics software. This link included researcher contact information so potential participants could request a paper copy of the questionnaire. Participants encountered the consent form in both the online and paper surveys before they started the survey. Each participant was required to either sign a paper survey to indicate consent or continue completing the online survey, which indicated consent. On average, the survey took between 15 and 20 minutes to complete. After completing the survey, participants were directed to a separate survey to provide a mailing address to receive a \$25 VISA gift card compensation. Using two different surveys kept the responses anonymous. The compensation came from this research's funding from Brigham Young University's Women's Research Initiative Grant. The VISA gift cards were mailed with thank-you notes inviting the participants to tell their eligible friends about the study.

Research Design

The research design was correlational and used structural equation modeling (Kline, 2010). Structural equation modeling was used because it controlled for measurement error, allowed multiple measures for variables, and allowed for simultaneous examination of both indirect and direct paths between variables. The independent variable in this study was respite care, the dependent variable was depression, and the two mediating variables were (a) stress as measured by caregiver burden and daily hassles and (b) daily uplifts.

A possible threat to this study's validity is the use of self-reporting rather than observed behaviors. However, the questions were very specific to help participants more accurately observe and report their behaviors. Another threat to validity is the fact that the Respite Care Instrument has not been validated. Limitations to external validity are the small sample size ($N = 122$) and that over 50% of the data came from the same region of the country. All responses were received through the Internet, which limited respondents to those having access to the Internet. We controlled for this by offering a paper copy of the questionnaire participants could request by phone or e-mail; however, even though we received requests for paper copies, none were returned. Another concern was that participants' Internet access may have failed or a participant may have started but not finished answering a questionnaire (93 surveys were started but not completed). About 65% of surveys started were completed (169 of 262). Qualtrics software makes it possible for a participant to click on the link again and start where the survey left off (as long as the participant is participating from the same IP address); however, it is not possible to determine which surveys were started more than once. Finally, participants may have exaggerated their symptoms with the hope that study results would provide more funding for

respite care or underestimated their symptoms to indicate greater levels of resiliency than they currently experienced.

Data Analysis

After calculating descriptive statistics (including means, standard deviations, and correlations for all variables) using Statistical Package for the Social Sciences, we then used structural equation modeling in Mplus, version 6 (Muthén & Muthén, 2006), to test the relationships between respite care and depression with stress and uplifts as mediating variables. Unstandardized and standardized beta coefficients were calculated in order to determine the strength of the relationships (direct and indirect paths) between the variables in the structural model. To estimate if stress and uplifts mediated the relationship between respite care and depression, bias-corrected bootstrapping with 2,000 draws was used (Preacher & Hayes, 2008). Significance levels were set at $p < .05$ for all study variables.

Results

One hundred sixty-nine surveys were submitted online; however, only 122 contained useable responses. Forty-seven surveys were not included because they were not fully completed, had questionable data due to incongruences in reported location and actual Global Positioning System location, or had responses identical to another survey. This study consisted of data from 122 single mothers of children with ASD. These mothers' demographics appear in Table 1.

Respite Care

Seventy-three of the 122 (59.8%) mothers accessed some form of respite care. Of the forms of respite care accessed by these 73 single mothers, 24.6% ($n = 18$) of the care was provided by grandparents, 13.6% ($n = 10$) provided by a community agency, 10.9% ($n = 8$)

provided by extended family, 6.8% ($n = 5$) provided by a babysitter, 2.7% ($n = 2$) provided by “other,” and 41.0% ($n = 30$) was provided by a combination of the different providers of respite care. Seventy-one percent of the mothers ($n = 73$) were satisfied or highly satisfied with the respite care received, and 29% were neutral or dissatisfied with the respite care. See Table 2 for more information related to the demographic characteristics of the children with ASD and the respite care their mothers received.

Correlations and Means

Mothers reported mean respite hours of 6.98 per week ($SD = 10.70$). The mothers’ mean hassles frequency score (the average number of times a mother indicated items as stressful) was 33.14 ($SD = 10.76$), suggesting slightly over 60% of the 54 items were annoyances or bothers. In contrast, mothers’ mean uplift frequency score (the average number of times a mother indicated items as uplifts) was 26.84 ($SD=12.06$), suggesting 48% of the 54 items were satisfying or glad. The hassles sum of intensity scores were relatively high, with a mean of 117.83 ($SD = 31.14$), while the uplifts sum of intensity scores were lower, with a mean of 99.83 ($SD = 26.35$), out of a sum total of 212 for each measure.

Single mothers’ report of respite care hours was weakly positively correlated with reported intensity of daily uplifts ($r = .15, p < .05$; see Table 3). This means mothers who reported higher amounts of respite care were somewhat likely to also report a greater number of daily uplifts. However, the relationships between amounts of respite care hours and caregiver burden, daily hassles, and depression were not significant.

The correlation between intensity of hassles and caregiver burden was .73 ($p < .001$) and intensity of hassles and frequency of hassles was .86 ($p < .001$), meaning the measures of stress were significantly positively correlated. The correlation between intensity of uplifts and

frequency of uplifts was .91 ($p < .001$) meaning the measures of uplifts were significantly positively correlated.

Reports of daily uplift intensity scores were negatively correlated with reports of depression ($r = -.17, p < .05$). This means that mothers who reported more daily uplifts on average reported fewer symptoms of depression. Intensity of daily hassles significantly positively correlated with depression ($r = .66, p < .001$), meaning as daily hassles increased, mothers reported more depressive symptoms. Similarly, there was a significant positive relationship between caregiver burden and depression ($r = .61, p < .001$).

Structural Model Results

Figure 2 shows the relationship between each of the variables in the structural equation model, standardized beta coefficients of each pathway with stress and uplifts as potential mediators. In order for the hypothesized model to be considered a good fit to the data, χ^2 values need to be nonsignificant; the comparative fit index (CFI) needs to be above .95; the root mean square error of approximation (RMSEA) needs to be less than .05; and the standardized root mean square residual (RMSR) needs to be less than .08 (Kline, 2010). The overall fit indices indicate the model was a good fit for the data ($\chi^2 = 3.61, df = 8, p = .11$); the CFI was .981, the RMSEA was .041, and the RMSR was .044.

Hypothesis 1 results: Amount of respite care and depressive symptoms. Hypothesis 1 stated that for single mothers of children with ASD there would be a significant negative relationship between the amount of respite care and depressive symptoms. The data in figure 2 show there was a nonsignificant negative relationship between the amount of respite care and depression ($\beta = -.09$). Therefore, hypothesis 1 was not supported.

Hypothesis 2 results: Amount of respite care and stress. Hypothesis 2 stated that for single mothers of children with ASD there would be a significant negative relationship between the amount of respite care and stress as measured by daily hassles and caregiver burden. Figure 2 shows there was a negative relationship between the amount of respite care and stress ($\beta = -.02$), but it was not statistically significant. Therefore, hypothesis 2 was not supported.

Hypothesis 3 results: Amount of respite care and daily uplifts. Hypothesis 3 stated that there would be a significant positive relationship between the amount of respite care and daily uplifts. Figure 2 shows there was a positive relationship between the amount of respite care and daily uplifts ($\beta = .15, p < .05$), meaning that as respite care increased, the intensity of daily uplifts increased. Therefore, hypothesis 3 was supported.

Hypothesis 4 results: Stress as a mediator between respite care and depression. Hypothesis 4 stated that stress, measured by daily hassles and caregiver burden, would mediate the relationship between the amount of respite care and depression. Bootstrap results showed the size of the indirect effect ($-.11, SE = .048, 95\% CI = -.312$ to $-.183, p = .24$) was nonsignificant, suggesting stress did not mediate the relationship between respite care and depression. Therefore, hypothesis 4 was not supported ($\beta = -.02$ between respite care and stress; $\beta = .76, p < .001$ between stress and depression).

Hypothesis 5 results: Uplifts as a mediator between respite care and depression. Hypothesis 5 stated that daily uplifts would mediate the relationship between the amount of respite care and depression. The size of the indirect effect ($-.23, SE = .04, 95\% CI = -.425$ to $-.012, p < .01$) was significant, meaning uplifts significantly mediated the relationship between respite care and depression and hypothesis 5 was supported ($\beta = .15, p < .05$ between respite care and uplifts; $\beta = -.24, p < .01$ between uplifts and depression).

Discussion

This research is an extension study of Harper et al.'s (2013) study, "Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders," which examined married parents' experiences of raising children with ASD and focused on the relationships among respite care, marital quality, and stress. The purpose of the current study was to examine single mothers' experience raising children with ASD, focusing on the relationships among respite care, stress, daily uplifts, and depression. Following a discussion of the differences between single and married mothers of children with ASD, the following topics will be discussed: respite care and its relationship to depression with uplifts as a mediating variable, respite care and depression, and respite care and stress.

Single Mothers and Married Mothers of Children with ASD

Although it is not possible to make firm conclusions about these single mothers and the married mothers in Harper et al.'s (2013) study, it is interesting to describe the typical characteristics of a single and married mother of a child with ASD in these two studies. The majority of both of these groups of mothers were non-Hispanic White and most were from the West or Rocky Mountain Regions of the United States.

A typical single mother of a child with ASD from this study is about 36 years old and has on average 2 children, including TDC. She is likely living in poverty (<\$25,000 annually) and is at risk for clinical depression. She receives an almost seven hours of respite care weekly. Her stress levels do not decrease as she receives respite, while her uplifts are likely to significantly increase ($\beta = .15, p < .05$) as she receives respite care. She appears to spend her respite care time working, running errands, and catching up on responsibilities, with limited relaxation.

A typical married mother of a child with ASD from the Harper et al.'s (2013) study is about 38 years old has on average 3 children including TDC. She is likely to be living in a household that earns an average of at least \$50,000 annually. She receives almost seven hours of respite care weekly. Her stress levels are likely to significantly decrease ($\beta = -.32, p < .001$) and her uplifts significantly increase ($\beta = .21, p < .01$) as she receives respite care.

Single mothers in this study were more likely than married mothers in Harper et al.'s (2013) study to be at risk for poverty (Atkins, 2010) and to experience more parenting stress (Cairney et al., 2003). Although there is not a comparison for married mothers on the depression measure, previous research has found single mothers to be more likely to be depressed than married mothers (Cairney et al., 2003; Wang, 2004). Married mothers may have more access than single mothers to family support, such as a husband or in-laws, outside of formal respite care services. Bromley, Hare, Davison, and Emerson (2004) found more family support to be associated with less psychological distress, which may explain why married mothers' stress decreases when receiving respite care, assuming that respite care is in addition to family support.

Respite Care and Depression with Uplifts as a Mediator

Previous research indicates that respite care is associated with lower psychological distress of primary caregivers of children with developmental disabilities and ASD (Ekas & Whitman, 2010; Mullins et al., 2002). The most notable finding in the current study supports and contributes to these findings because respite care was found to be associated with decreased depressive symptoms in single mothers of children with ASD when taking into account daily uplifts. In addition, daily uplifts were a significant mediating variable between the amount of respite care received and symptoms of depression, indicating uplifts were a process through

which respite care indirectly affected depression. It may be that positive perceptions of daily events (uplifts) help explain decreased depressive symptoms.

McCubbin's model of family adaptation suggests positive appraisals of a crisis, in this case being a single parent of a child with ASD, are related to fewer negative outcomes, meaning that if a parent is able to view the crisis event as nonthreatening they are less likely to experience negative outcomes, which, in this study, may be depressive symptoms (McCubbin & Patterson, 1983; Pakenham, Samios, & Sofronoff, 2005). Plant and Sanders (2007) also found a mother's cognitive appraisal of the level of a child's disability was directly related to stress levels, meaning the more negative a mother perceived her child's disability, the more stress she experienced. During the time the child is receiving respite care, single mothers may work to earn money, engage in uplifting social interactions, or participate in activities leading to more uplifts throughout the day. Consequently, respite care may lead to more positive outlooks because it may help develop coping strategies, such as positive appraisal, for single mothers.

Single mothers in this study and married mothers in the Harper et al.'s (2013) study reported more daily uplifts as respite care amounts increased; however, single mothers' levels of stress did not decrease as daily uplifts increased, as they did in the Harper et al.'s (2013) study. Ekas and Whitman (2010) studied the impact of a daily positive affect as a protective factor against stress and negative affect for mothers (married, divorced, widowed, and single) of children with ASD and found benefits of positive affect when levels of stress were low or moderate. However, when stress levels were high, positive affect did not buffer against the negative effects of stress. Perhaps single mothers of children with ASD experience high levels of stress so frequently that they are less likely to report more daily uplifts than daily hassles compared to married mothers.

Respite Care and Depression

Most single mothers in this study (77%; $n = 94$) were at risk for clinical depression. Although 59.8% ($n = 73$) of these mothers reported receiving respite care, many continued to experience depressive symptomology. Perhaps a greater amount of respite care is needed in order to buffer the effects of depression in these mothers, or perhaps there are other mediating variables explaining the relationship between respite care and depression. For example, Carter et al. (2009) found low social supports and maternal coping styles were associated with depression severity in mothers of children with ASD. When comparing married mothers to single mothers, Cairney et al. (2003) found single mothers reported more adversities from their childhood, such as divorce of parents, physical abuse, or hospitalization; more negative life events such as financial crises, unwanted pregnancies, or abuse; and higher levels of chronic stress than married mothers. According to Davies, Avison, and McAlpine (1997), childhood adversities also increase the likelihood of early onset depression for mothers.

Single mothers in this study were non-cohabitating, which may lead to them experiencing more stress than cohabitating single mothers. This is in line with Cooper, McLanahan, Meadows, and Brooks-Gunn (2009), who found parenting stress levels were higher in mothers who remained single rather than in those who cohabitated with the biological father. Similarly, Tietler, Reichman, and Nepomnyaschy (2004) found unwed cohabiting mothers were about one-third as likely as non-cohabitating mothers to experience depression. Having a live-in partner may help mothers emotionally cope with stress, particularly stress related to burdens associated with providing care to a child with disabilities.

Respite Care and Stress

Cowen and Reed (2002) found providing both married and single parents of children with disabilities a break from the demands of parenting significantly reduced their stress levels. These findings were not supported by this study, however, as the levels of stress in single mothers did not decrease as respite care hours increased. This may be explained by other mediating variables not examined, such as financial and job stresses of being a single parent coupled with the lack of consistent parenting support from a spouse.

Single mothers experience more stress than married mothers. For example, Copeland (2005) found that first-time single mothers of TDC reported significantly higher levels of stress than married mothers within the first six to eight weeks after giving birth. Mothers of TDC also experience less stress than mothers of children with disabilities (Hoffman et al., 2009), and mothers of children with ASD have higher levels of stress than mothers of children with other disabilities (Griffith et al, 2010; Rao & Beidel, 2009; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). When considering single mothers of children with ASD in the current study, it is important to note the high levels of stress they experience being (a) a single mother (b) a single mother of a child with a disability, and c) a single mother of a child with ASD. Single-mother stress in the current study was higher than married-mother stress in the Harper et al.'s (2013) study. Perhaps a pileup of stressors (see Pakenham et al., 2005), such as lack of a partner to share parenting responsibilities, financial strains, or lack of social support, is related to greater levels of stress for single mothers of children with ASD compared to married mothers of children with ASD.

In the current study, the amount of respite care did not decrease stress for single mothers as it did for married mothers in the Harper et al. (2013) study. This may be because single

mothers experience more chronic stress than married mothers (Cairney et. al, 2003; Thompson, 1989). Single mothers also experience stress from multiple sources, such as limited finances and employment difficulties, dating hassles, or hassles with a former partner. Respite care may not decrease these kinds of stressors, whereas stressors for married mothers may be more related to typical daily challenges such as housework, lack of free time, and typical parenting hassles. Cairney et al. (2003) explained the higher level of chronic stress single mothers experience, calling it a “saturation” effect. Here single mothers are more accustomed to stressful life events and less reactive to them because of high levels of chronic stress they experience. This “saturation” effect may also explain why in this study, respite care did not decrease stress in single mothers. Perhaps single mothers are less reactive to stressful life events due to high levels of stress and therefore their stress levels may not be impacted by respite care.

Caregivers of children with ASD may also be more likely than caregivers of children with other conditions to have difficulty accessing services. For example, Vohra, Madhavan, Sambamoorthi, and St. Peter (2013) found caregivers of children with ASD were more likely than caregivers of children with other developmental disabilities (DD) and mental health conditions (MHC) to report difficulty accessing services, difficulty finding sources of care, and adverse family effects. In fact, Vohra et. al (2013), found 25.8% of caregivers of children with ASD reported limited availability of services compared to 11.8% of caregivers of children with DD and MHC. Interestingly, most single mothers of children with ASD (59.8%; $n = 73$) in the current study reported receiving some form of respite care. This may mean these single mothers overcame difficulties in order to find respite care from community sources, or family respite support was strong.

Single mothers access more services than married mothers. For example, Floyd and Gallagher (1997) found that while single mothers of children with mental retardation and chronic illness did not report more stress than married counterparts, they used more support services (such as community agency or mental health services) than married mothers, which is consistent with our results. Of the children receiving respite care in the current study, 42.6% received respite care from more than one source, while only 6.6% of married parents in the Harper et al. (2013) study received respite care from more than one source. Floyd and Gallagher (1997) argued that single mothers might access more services due to a lack of other coping resources such as financial resources and consistent parenting support. Or, as Floyd and Gallagher (1997) explain, the need for services is not only explained by stress, but by unavailability of other resources.

Respite Care

It may be that a greater amount of respite care is needed in order to make an impact on stress and depressive symptoms of single mothers of children with ASD. In the current study, the mean number of weekly hours of respite care was 6.98 hours. This could mean that these single mothers were, on average, accessing respite for one hour a day or for approximately seven hours in one day. An increased dosage of respite care might make a difference depending on how the time is used by these mothers. To understand other variables that may increase or decrease stress, it is important to know what the single mother is doing while receiving respite care and what coping strategies they use. Like one single mother reported in this study, “[While my child is receiving respite care], I'm usually catching up on house work, yard work, getting car repairs done, doctor appointments for myself. Rarely have time to relax.” Of the 73 mothers accessing respite care, 24 mothers (32.8%) mentioned spending their time working while their child was

receiving respite care. Fifteen mothers (20.5%) said they ran errands. Other mothers reported taking naps, going to dinner with friends, going on walks, or doing housework. It is important to note that these responses are not the result of a structured, thorough analysis of qualitative responses, but a sample of responses.

Limitations

This study is limited in scope due to the small sample size of such a specific population. If the sample size were larger, more correlational relationships may be statistically significant. Additionally, most participants were non-Hispanic White (71.3%) and living in the West region of the United States (53.3%) which makes them relatively homogenous. These similarities make it difficult to generalize findings to other populations and cultures.

This study is limited because it is cross-sectional and therefore it is not possible to make conclusions about the directions of the relationships between variables. For example, we cannot conclude whether uplifts have an effect on depression or if depression has an effect on uplifts. A longitudinal study could confirm the order of variables.

Additionally, this study is limited due to self-report. There was no way for researchers to confirm reported information. Factors were assessed by different measures, including the Respite Care Questionnaire, which has not been validated. Lastly, this study was limited to those single mothers who had access to the Internet, as most of the recruiting was completed online. Although a paper copy was available upon request, many single mothers may have been excluded who did not have Internet access or request a paper copy.

Implications for Future Research

To the best of our knowledge, this is the first study to quantify respite care received by single mothers of children with ASD, and there is little research documenting experiences of

single mothers of children with ASD. The literature discusses increased parenting stress for single mothers and more especially single mothers of children with ASD; however, there is no research focused specifically on the impact of respite care on single mother perceptions of depression, stress, and uplifts. Therefore, this study evokes more questions, such as whether or not single mothers' levels of depression, stress, and uplifts would be different if they had more respite care. Is there a certain dosage of respite care needed in order to make a difference for these single mothers? What other forms of relief are available to single mothers besides respite care? Is respite care accessible to single mothers of children with ASD? What kind of social supports do non-cohabitating single mothers utilize? What are the specific sources of stress experienced by single mothers? Although previous studies have had difficulty gathering data about single fathers, it would be important to understand single father perceptions as well.

Implications for Practitioners

Policymakers should consider developing policies requiring schools and organizations to provide respite care to single mothers of children with ASD, as respite care may make a positive difference in the lives of these mothers. Also, since single parents may struggle to attend school or community sponsored events such as parent training classes, parent-teacher conferences, and Individualized Education Program meetings, education professionals are advised to provide respite care so parents can be engaged in these important activities. There may be additional interventions that would make a difference for these single mothers, and policymakers should support the development, funding, and implementation of these interventions. For example, Sorensen, Pinqart, and Duberstein (2002) studied caregiver interventions for adult patients and found that psychoeducational interventions decreased caregiver burden and depression and improved caregiver well being, knowledge, and ability.

School personnel, such as teachers, school social workers, and school psychologists, should be made aware of the relationship between respite care and increased reports of daily uplifts which may be related to decreased symptoms of depression in single mothers of children with ASD. It would be helpful for school personnel to learn about the informal and formal organizations in their communities that provide respite care services and share that information with single mothers of children with ASD. It could be beneficial to have a referral system in the school system that would link single mothers to respite care service providers. Finally, respite care service providers could be invited to attend individualized education program meetings in the school setting, and options for mental health services could also be addressed during these meetings.

Conclusion

Single mothers of children with ASD are not fully represented in research regarding parenting children with ASD. As the number of single-parent families grows along with the increased prevalence of children diagnosed with ASD, it is important to understand these mothers' experiences. Even though most of our hypotheses were not supported, our findings contribute to the literature regarding parenting children with ASD.

Study findings provide evidence that single mothers of children with ASD are likely to experience depressive symptoms and access multiple sources of respite care. Seventy-seven percent of surveyed single mothers of children with ASD would be considered at risk for clinical depression based on their responses on the CES-D scale. Over half of the single mothers (59.8%; $n = 73$) in this study accessed respite care services and 41.0% ($n = 30$) received respite care from multiple sources, suggesting these mothers know how to access formal and informal resources. Finally, respite care was associated with decreased symptoms of depression for single

mothers who reported more daily uplifts, meaning respite care may lead to more positive appraisals of daily events (uplifts), which may, in turn, lead to fewer symptoms of depression.

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Table 1

Demographic Characteristics of Single Mothers of Children with ASD (N = 122)

Variables	Single Mothers Mean (SD)
Age	36.6 (6.96)
Number of Children	2.14 (1.04)
	Percentages
Relationship Status	
Single (separated, divorced, widowed)	76.2
Single (never married)	23.8
At Risk for Clinical Depression (determined by CES-D cut off of 15)	77.0
Household Income	
Less than \$7,000	7.4
\$7,001 to \$15,000	22.1
\$15,001 to \$25,000	19.7
\$25,001 to \$35,000	12.3
\$35,001 to \$50,000	17.2
\$50,001 to \$65,000	13.1
\$65,001 to \$80,000	2.5
\$80,001 to \$95,000	3.3
>\$95,001	<2.5
Education	
Less than High School	0.0
High School Graduate	13.4
Completed Some College	26.5
Bachelor's Degree	43.5
Master's Degree	12.5
Doctorate/Professional Degree	5.1
Race/Ethnicity	
African American	11.5
African American/Hispanic	1.6
African American/White	2.5
Asian	0.8
Hispanic	2.5
White/Hispanic	9.0
White	71.3
Other	0.8
Geographic Region	
Northeast	9.0
Midwest	13.1
South	21.3
West	53.3
Foreign	2.5
Other	0.8

Table 2

Demographic Characteristics of Children with ASD (N = 142; 30 females; 112 males)

Variables	Medical Diagnosis									
	Autism		Asperger		Pervasive Developmental Disorder-NOS		Autism Spectrum Disorder		Non-Medical ASD Diagnosis	
	Male Number	Female Number	Male Number	Female Number	Male Number	Female Number	Male Number	Female Number	Male Number	Female Number
Birth Order of Child										
1 st	37	7	8	2	3	3	3	0	12	2
2 nd	18	8	3	1	3	0	3	2	3	0
3 rd	4	2	2	0	2	0	2	0	2	2
4 th	4	0	0	0	2	0	0	0	0	1
5 th	1	0	0	0	0	0	0	0	0	0
Gender	64	17	13	3	10	3	8	2	17	5
Age Mean (S.D.)	7.85 (4.29)	7.00 (4.06)	12.16 (5.82)	11.50 (2.12)	12.40 (6.04)	6.67 (2.31)	9.42 (5.38)	5.50 (2.12)	10.75 (4.83)	11.2 (3.89)
% Receiving Respite	62.5%	64.7%	61.5%	0.0%	40.0%	66.7%	37.5%	0.0%	64.7%	60.0%
Number Receiving Respite	40	11	8	0	4	2	3	0	11	3
Type of Respite										
Grandparents	9	3	2	0	1	0	0	0	2	0
Extended Family	1	2	3	0	0	0	1	0	2	1
Babysitter	3	1	0	0	0	0	0	0	1	0
Community Agency	12	0	1	0	0	0	0	0	0	0
Other	0	0	0	0	0	0	0	0	1	1
Combination	15	5	2	0	3	2	2	0	5	1

Table 3

Correlations, Means, & Standard Deviations for All Variables

	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Respite	1.0												
2. Hassles Intensity	-.07	1.0											
3. Hassles Frequency	-.01	.86***	1.0										
4. Caregiver Burden	-.01	.73***	.59***	1.0									
5. Uplifts Intensity	.15*	.10	.23**	.10	1.0								
6. Uplifts Frequency	.16*	.12	.28***	-.01	.91***	1.0							
7. Depression	.07	.66***	.50***	.61***	-.17*	-.21**	1.0						
8. Age of Mother	-.08	.05	.02	.06	.03	.01	.05	1.0					
9. Race (White/Other)	.05	.07	.06	.05	.12	.11	.03	-.06	1.0				
10. Income	-.01	-.09	.09	-.12	.11	.10	-.06	.12	.18*	1.0			
11. Region	.04	-.04	.04	.06	.07	.04	.05	.10	-.22**	.04	1.0		
12. Day Care	-.09	.04	.08	.05	.07	.11	.05	-.38*	-.02	.22**	-.06	1.0	
13. Education	.10	-.11	-.11	-.10	.09	.12	-.06	.29***	.01	.44***	.02	.01	1.0
Mean	6.98	117.83	33.14	99.04	99.83	26.84	46.31	36.67	---	---	---	8.86	---
Standard Deviation	10.70	31.14	10.76	20.49	26.35	12.06	9.38	6.96	---	---	---	13.28	---

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

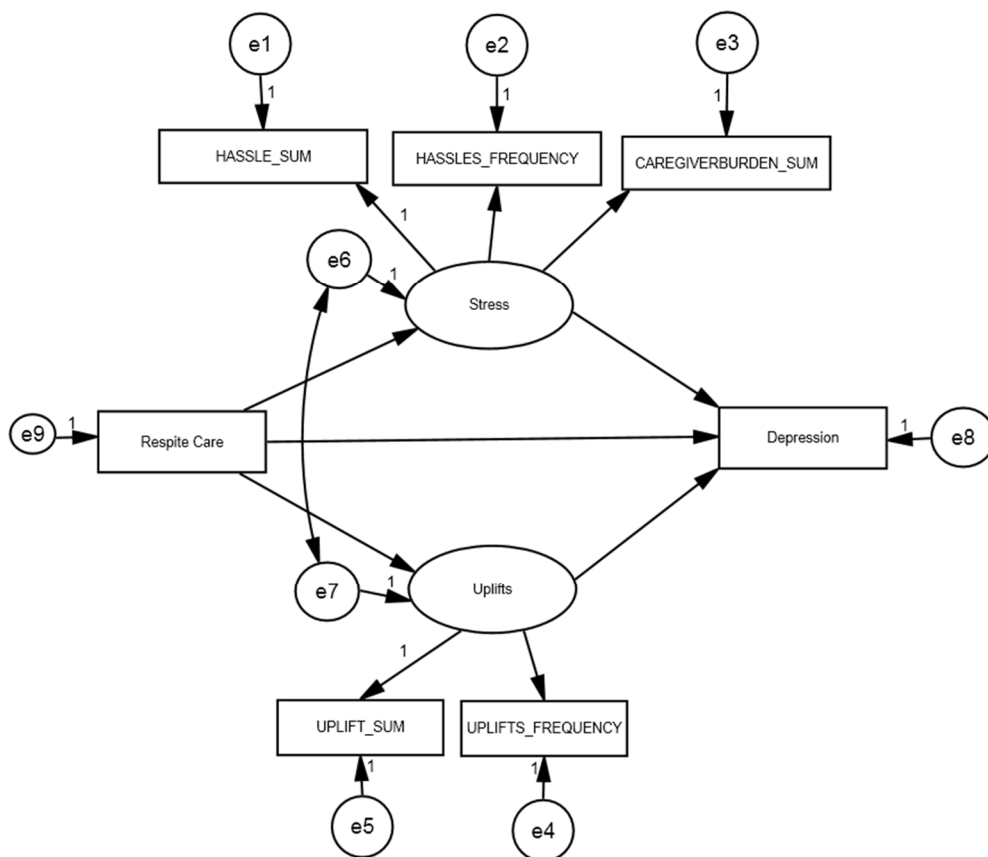


Figure 1. Measurement and hypothesized structural equation model.

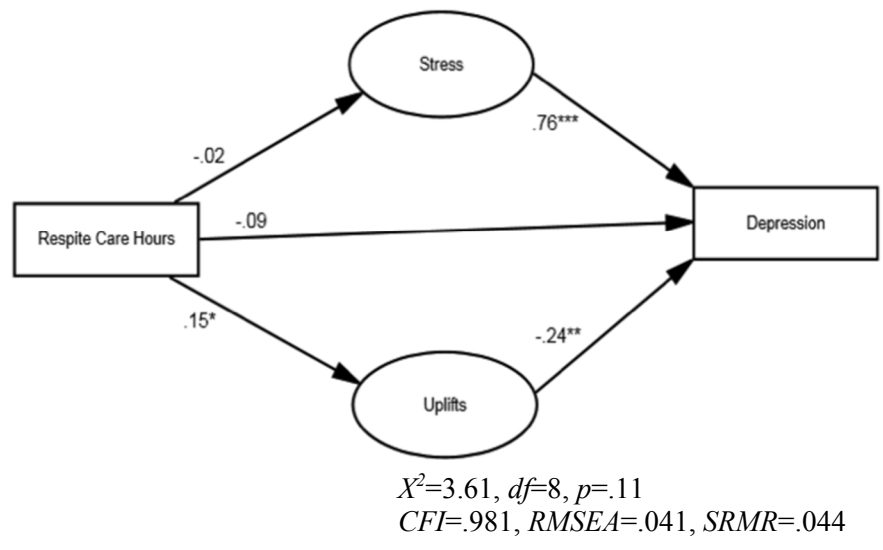


Figure 2. Structural equation model results with respite care hours predicting depression with stress and uplifts as mediators. Age of mother, race of mother, education, income, region, and daycare hours were control variables, but since none of them were statistically significant predictors, they are not included in this figure. * $p < .05$, ** $p < .01$, *** $p < .001$

APPENDIX A: Review of Literature

The following is a review of literature discussing the existing research regarding parenting children with autism spectrum disorder (ASD). Depression, social support, respite care, factors influencing parental stress, and current knowledge regarding their relationships will also be examined. A brief review of parenting children with and without disabilities sets the stage for understanding single mothers of children with ASD. Raising a child with ASD is difficult, and single mothers of even TDC experience greater stress than married mothers (Copeland, 2005). Single mothers may have less support raising their child without a spouse. However, parental stress, depression, lack of social support, difficult child behaviors, and financial strains may be buffered by more access to respite care, which gives mothers a break from parenting stress, positively impacting their quality of life.

Stressors Related to Parenting

The transition to parenthood is one of the most significant events in the life of an individual (Feeney, Hohaus, Noller, & Alexander, 2001), and as millions of couples undergo the transition to parenthood each year, this topic has been interesting to many researchers. The birth of an infant makes the relationship of the couple more complex, because they have to focus on the child's needs (Feeney et al., 2001). However, the joys of becoming a parent often offset difficulties of parenthood (Huston & Holmes, 2004).

New parents often report they have less leisure time, more stress due to money and job changes, and feelings of less intimacy within the marriage than parents without children (Doss, Rhoades, Stanley, & Markman, 2009). In an eight-year study aimed at assessing couples' relationship functioning before and after the birth of a child, many aspects of the relationship deteriorated rapidly immediately after the birth of a child (Doss et al., 2009). Specifically,

relationship satisfaction decreased, problem intensity increased, and more negative communication and poor conflict resolution occurred. “For the average couple, no aspect of relationship functioning showed a positive effect of the transition to parenthood” (Doss et al., 2009, p. 610). These negative effects tended to persist for up to four years after the birth of the child.

McCubbin’s Double ABCX Model

One model particularly useful for studying families is McCubbin’s Double ABCX Model (McCubbin & Patterson, 1983), which is useful when investigating factors related to families raising children, and addresses coping mechanisms applied in stressful situations (Pakenham, Samios, & Sofronoff, 2005). McCubbin’s model is an outgrowth of Hill’s ABCX model, which combines the stressor (A), the family’s resources for meeting crises (B), and how the family defines the stressor (C) to either create or prevent a family crisis (X). McCubbin’s model introduces four additional factors contributing to familial adjustment: the severity of the stressor (aA); not just the resources, but which resources are applied to the crisis situation (bB); the way a definition of the stressor may change in order for the family to better understand the stressor (cC); the coping strategies used (BC); and the outcomes of the family’s efforts/adjustment (Pakenham et al., 2005).

The severity of the stressor (aA) according to McCubbin’s model is important to take into account, because the more severe the stressor the more crisis the family may experience. It is also unrealistic to believe a family experiences only one stressor. Stressors accumulate after experiencing an initial stressor within the family, which can lead to crisis (Pakenham et al., 2005).

Adaptive resources (bB) determine how a family perceives a stressor and include financial, social, and psychological resources. Social resources include family and friend support systems as well as help through community organizations such as schools. Psychological resources, on the other hand, come from within the person or family and include resources such as coping strategies, perspective, attitude, and resilience.

The meaning a family creates about a crisis event, or their appraisal (cC), is the combination of the initial stressor, additional stressors, perceived adaptive resources, and what the family believes is needed to overcome the crisis. Positive appraisals are correlated with lower parenting stress, meaning that if parents are able to view the crisis event as a nonthreatening event then they are less likely to experience parenting stress (Pakenham et al., 2005)

Coping (BC), according to McCubbin's model, is when the interaction between appraisal, resources, and subsequent behaviors restores order and balance to the family. Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as having or exceeding the resources of the person" (p. 141). Outcomes (XX) are family efforts employed to create a new level of balance within the family in response to the stressor. Adjustment may include life satisfaction, level of physical health, social adjustment, and psychological distress such as depression and anxiety.

With this model in mind, the focus will be turned to how families respond to the stressor of having a child with disabilities. Raising a typically developing child (TDC) is demanding, but the addition of a disability can create more demands on the family (King, 2006). These additional demands may be related to parental stress.

Stressors Related to Parenting Children with Disabilities

For the purposes of this review, a TDC is one who is not receiving special education services. According to the Individuals with Disabilities Education Improvement Act, a child with a disability means

a child evaluated... as having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to... as 'emotional disturbance'), an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services. (U.S. Department of Education, Section 300.8(a)(1), n.d.)

Indeed, raising a child with any kind of disability would add to one's parenting stress as the parent would spend more time and resources in caring for their child.

The transition to parenthood for parents of a child with disabilities differs from the transition experienced by parents of TDC. According to Heiman (2002), parents often experience feelings of depression, shame, self-blame, stress, and guilt when they learn their child has a disability. A mother's cognitive appraisal of the level of disability of her child is directly related to her level of stress, suggesting the more negatively the mother perceived the disability, the more stress she experienced (Plant & Sanders, 2007).

Much of the stress mothers of children with disabilities experience may be due to physical and emotional demands of raising these children. For example, based on responses from 105 mothers of preschool-aged children with developmental disabilities, Plant and Sanders (2007) noted that difficult tasks (e.g., bathing, going to doctor's appointments, supervision),

along with difficult child behavior and the level of disability contributed to maternal stress. In addition, Murphy, Christian, Caplin, and Young (2007) found caregivers of children with disabilities experience negative emotional and physical health due to caregiving tasks and anxiety about their child's wellbeing. One disability that has been shown to significantly impact family functioning, and therefore may result in increased negative caregiver outcomes, is autism spectrum disorders (ASD).

Autism Spectrum Disorders

ASD refers to a range of concerning developmental symptoms exhibiting themselves within the first three years of life. The *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*; American Psychiatric Association, 2013) identifies four criteria that must exist to receive a diagnosis of ASD, including (a) persistent impairments in social communication and reciprocal communication, (b) restricted and repetitive behaviors, (c) symptoms present since early childhood, and (d) symptoms limiting or impairing daily functioning (American Psychiatric Association, 2013).

ASD is currently viewed as an epidemic in the United States and considered an important public health concern, with estimates of 1 in 68 children (or 14.7 per 1,000 8-year-olds) being identified (Centers for Disease Control and Prevention, 2014). This increasing prevalence, up from 1 in 88 children reported in 2012, indicates an increasing number of families raising these children.

Stressors Related to Parenting Children with ASD

Raising a child with ASD is difficult and described as a psychologically distressing experience (Ekas & Whitman, 2010). The literature consistently reports levels of parenting stress is higher in mothers of children with ASD than in mothers of both TDC and children with

other developmental disabilities (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Rao & Beidel, 2009; Schieve, Blumberg, Rice, Visser, & Boyle, 2007).

Researchers administered the Parenting Stress Index (PSI) to 104 mothers of children with a classification or diagnosis of autism and 342 mothers of TDC; mothers of children with autism were reported to have significantly higher levels of stress (Hoffman et al., 2009). The PSI assesses whether parental stress can be attributed to child-related factors or to parent-related factors. Results indicated that mothers of children with autism had higher stress levels in both the Child Domain and the Parent Domain. Parents who score at or above the 90th percentile in the total score on the PSI are experiencing significant levels of stress (Abidin, 1995). The results of the Child Domain scale of mothers of TDC fell in the 40th percentile while mothers of children with autism fell in the 99th percentile. The Parent Domain percentiles were as follows: 45th percentile for TDC and 75th percentile for autism.

Parents of children with ASD also report having more concerns about their children than parents of TDC or children with ADHD (Lee, Harrington, Louie, & Newschaffer, 2008). Parents of children with ASD were more concerned than other parents about their child's future, potential learning disabilities, and bullying. Dale, Jahoda, and Knott (2006) interviewed mothers to assess how they responded to the diagnosis of ASD and found most mothers were concerned about their child's future and responded more positively when they had help to make sense of the diagnosis.

Financial strains are also common among parents of children with ASD. According to Montes and Halterman (2008), 14% of the income of families of children with ASD is lost due to expenses required for caring for these children. Having a child with ASD also decreased the odds of living in a higher-income household, and these parents were more negatively affected financially by the need for childcare services and how that need dictated their employment

decisions. Finally, parents of children with ASD were seven times more likely to report they quit their job, not take a job, or changed their job based on the need for childcare services. Lee et al. (2008) reported greater childcare burden in families raising children with ASD, who were more likely to quit their job in order to take care of their child compared with parents of TDC and children with ADD/ADHD.

Depression in mothers of children with ASD. Many mothers of children with ASD are at risk for clinical depression. For example, Smith, Seltzer, Tager-Flusberg, Greenberg, and Carter (2008) found over one third of mothers raising toddlers or adolescents with ASD were at high risk for clinical depression, suggesting the length of the time since diagnosis did not lessen depressive symptoms. Taylor and Warren (2012) found about one third of mothers raising children with ASD reported clinically depressive symptoms the week following the ASD diagnosis of their child. In addition, 37% of mothers who reported depressive symptoms continued to report depression one year later. Carter, Martínez-Pedraza, and Gray (2009) found that low social supports and maternal coping styles were associated with the severity of depression of mothers of children with ASD, and the depressive symptoms did not lessen over time, but stayed the same. It was recommended that early intervention be implemented for mothers of children with ASD. One factor related to maternal depression according to Taylor and Warren (2012) was the child's behavior problems.

Challenging behavior of children with ASD. Parents of children with ASD probably experience more parenting stress because of the nature of behavioral challenges. For example, Baker, Blacher, Crnic, and Edelbrock (2002), Baker et al. (2003), and Baker, Blacher, and Olsson (2005) found children with developmental disabilities exhibit more problem behaviors than TDC. In addition, a child's behavior problems were associated with (Benson & Kersh, 2011;

Kersh, Hedvat, Hauser-Cram, & Warfield, 2006) and explained (Baker et al. 2002, 2003) levels of parenting stress (Lecavalier, Leone, & Wiltz, 2006). These findings are congruent when comparing mothers of children with ASD and mothers of children with Down syndrome and other intellectual disabilities. However, Griffith, Hastings, Nash, and Hill (2010) found mothers of children with ASD reported more problematic behaviors and higher stress levels than mothers of children with Down syndrome and mixed etiology intellectual disabilities. Finally, mothers raising a child who has high levels of behavior problems were at risk for psychological distress (Bromley, Hare, Davison, & Emerson, 2004).

Relationship between Divorce and Having Children with ASD

The popular media has reported that parents of children with ASD are 80% more likely to divorce (leading to single-parent homes) than parents of children without disabilities (Winfrey, 2007). However, according to Freedman, Kalb, Zablotsky, and Stuart (2012), there is insufficient evidence suggesting parents of children with ASD are more likely to divorce when compared to parents of children without ASD in the United States. In fact, after analyzing data from the National Survey of Children's Health, a total sample of 77,911 parent interviews with 913 reporting ASD, Freedman et al. (2012) found children with ASD were no more likely to live in a divorced parent home than a TDC. Although children with ASD may not be more likely to live in a divorced parent home than other children, single-parent homes are becoming more common in the United States than in the past.

Single-Mother Homes

McCubbin's model discusses the potential for a pileup of stressors leading to crisis, which seems apparent in the lives of most single mothers. After reviewing the data from the Fragile Families and Child Wellbeing Study (FFCW), Osborne, Berger, and Magnuson (2012)

found mothers who exited cohabiting or marital relationships within the first five years of the birth of a child were more likely to experience increased material hardships, depression, and parenting stress; along with decreased perceived social support.

According to the U. S. Census Bureau (Vespa, Lewis, & Kreider, 2013), 27% of the 39 million family groups studied in 2012 were made up of mother-only family groups, compared to 67% comprised of married couple homes. Children coming from these homes are four times more likely to be living in poverty; 36% of children from single-mother homes live in poverty, while only 9% of married parent homes lived in poverty (Vespa et al., 2013).

Depression in single mothers. According to research, there is a large disparity between married and single mothers in terms of depression. For example, in a study of 2,921 mothers (Cairney, Boyle, Offord, & Racine, 2003), single mothers were found to be twice as likely to have had depression in the previous year compared to married mothers. Wang (2004) confirmed that single mothers are more likely to be depressed and seek help from mental health professionals than married mothers. Wang also found single mothers or mothers who had poor general health were at risk for early onset depression in comparison to married mothers or mothers with better general health. Mothers reporting higher levels of social support had decreased risk of developing chronic postpartum depression. When mental health was measured there was a negative association between the amount of family support and the amount of reported distress, meaning that the less family support given to the mother, the more likely the mother was to experience psychological distress (Bromley et al., 2004).

Stress in single mothers. Single mothers face unique challenges. They experience different kinds of stressors than those experienced by married mothers, and they report higher levels of stress. For example, Cairney et al. (2003) found single mothers reported more

parenting stress than married mothers. Similarly, in a study that assessed maternal stress based on relationship transitions during the first five years of their child's life, Cooper, McLanahan, Meadows, and Brooks-Gunn (2009) discovered mothers who lived alone reported more parenting stress than mothers who cohabited with the child's biological father.

According to Cairney et al. (2003) single mothers reported less education and lower economic status than married mothers. Perhaps the lack of these resources contributed to more parenting stress. Combining stressors of single parenting with stressors of parenting a child with disabilities, it is likely stressors are compounded. Since females are more commonly reported to be the caregiver of a child with disabilities (National Alliance for Caregiving, 2009), it is important to understand their perceptions of being caregivers in order to aid them.

The research is limited when focusing on single mothers of children with ASD. However, single mothers of TDC are at an increased risk of poverty, depression, and elevated stress (Atkins, 2010). Single mothers report less total support, less family support, and less formal support than mothers with a partner (Cairney et al., 2003). These factors combined with the demands of raising a child with ASD could be problematic for single mothers and may mean they need more support than married mothers of children with ASD.

Support for Parents Raising Children with ASD

Social support minimizes parenting stress and stressors related to dysfunctional parenting behaviors (Pakenham et al., 2005). Cohen (2004) defines social support as “a social network's provision of psychological and material resources *intended to benefit an individual's ability to cope with stress*” (p. 676), which may be delivered as financial assistance, emotional support, or information or guidance.

Social support can also be perceived support received from three primary sources: friends, family, and significant others (Khanna et al., 2011) who found there are benefits to high levels of social support. In addition, social support is associated with a greater mental health–related quality of life (MHRQOL)—such as physical functioning, bodily health, vitality, social functioning, and mental health—for caregivers of children with ASD. Social support was a mediating variable between the impact of behavioral problems and its link to MHRQOL (Khanna et al., 2011). Likewise, social support decreased stress because it gave parents more of a sense of control in their lives (Siman-Tov, 2011). Finally, Dale et al. (2006) found social support decreased the family’s stress levels for families with children with ASD.

Another form of support is services provided by the community or schools for parents of children with ASD. For example, in Brookman-Frazer’s (2012) qualitative study of parents’ perspectives after receiving community mental health services for their child with ASD, the process of accessing services was particularly stressful for parents. Difficulties experienced while trying to access services were associated with negative family functioning such as marital discord, guilt, and feelings of isolation (Brookman-Frazer). Montes, Halterman, and Magyar (2009) found parents of children with ASD reported they were less satisfied with community health care services and school services than parents of other children with special health care needs (CSHCN). In fact, these parents were three times as likely to report the services their children needed were difficult to access. Reasons included too much paperwork, not enough money, long lines, services not available in the area, unqualified providers, lack of time, not being eligible, and poor communication between service providers. According to the parents of both children, difficulties in accessing services could have been due to informational and

communication barriers. However, parents of children with ASD were more likely than parents of CSHCN to report unavailable services and lack of skilled providers (Montes et al., 2009).

Another form of social support comes from marital relationships. In a study of 49 mothers who had positive perceptions of their children with ASD, mothers also reported having good marital relationships (Lickenbrock, Ekas, & Whitman, 2011). However, mothers who reporting negative perceptions of their children had negative marital relationships.

Support for Single Mothers Raising Children with ASD

Bromley et al. (2004) studied the perceived support of parents of children with ASD. Total support was determined by combining family support and informal and formal supports. Family support included other children, partner, parents or partner's parents, or relatives; informal support was categorized as friends or other parents; and formal supports included those provided in the schools. Single mothers and mothers who lived in unsuitable housing reported less total support, and mothers whose children had more disruptive behaviors reported less family support (Bromley et al., 2004).

Cairney et al. (2003) studied the relationship between depression, social support and stress. He found that high levels of stress and low levels of social support explained 40% of single mothers' depressive symptoms. This means mothers who experienced high levels of stress and reported low perceived social support were also reporting depressive symptoms.

Particularly for single parents of children with ASD, financial strain is impacted by time and effort expended in trying to access community mental health services for their children (Brookman-Fraze, 2012). If services were more readily available and accessible, single parents may take advantage of the services.

Respite Care as One Possible Solution to Reducing Stress

Respite care is typically defined as the temporary care provided for individuals with disabilities in an effort to give relief to the primary caregiver of individuals. Respite can be traced back to the 1950s and 1960s in England and was referred to as short term “relief care” for families of children with disabilities. These services generally took place in institutional settings (Stalker, 1990). In the 1970s, those benefitting from respite care demanded more flexibility than just receiving services in professional settings, and respite care centers were established in England (O’Brien, 2001). Respite care became somewhat popular during the 1980s and spread to other groups, such as the elderly and adults with disabilities (Stalker, 1990). After closely examining the literature about respite care from 1993 to 2002, Yun-Hee, Brodaty, and Chesterson (2005) found respite care is one of the few services focused on supporting the caregiver. Although caregivers may find satisfaction in their role, they also report a lower quality of life than non-caregivers and benefit both emotionally and physically when given a break from caregiving.

For caregivers of children with disabilities, respite care can be as simple as having a friend or family member watch the child for a short amount of time. It can also be a service provided by the community where the child is taken to a facility like a day care. In addition, there are respite care services available for emergency situations when the caregiver needs to attend to important matters and short-term services lasting a couple hours and long-term respite services extending overnight. Sometimes respite care is paid for by insurance, organizations, state agencies, or provided as a free service (Wayne & White, 2012).

According to the 2009 National Alliance for Caregiving/AARP National Caregiver Survey, which included caregivers of adults with disabilities as well as children with special

needs, 173 of 1,480 caregivers (14%) were caring for a child aged 0–17. If this were generalized to the population of the United States, it is estimated that 16.8 million care for children with special needs, and most caregivers in this population were females (72%). Twenty-one percent of caregivers (both male and female) were single never married, 16% separated or divorced, and 4% widowed. Those caring for a child or adolescent were more likely to use respite or sitter services (19%) compared to 11% of those caring for adults 50 and over.

Stress and respite care. One's stress is related to cognitive appraisal, depression, child behavior problems, financial strains, and lack of social support. Stress levels of parents of children with disabilities were reduced after receiving respite care interventions (Cowen & Reed, 2002). These investigations indicated that by giving parents of children with disabilities a break from the demands of parenting, stress levels were reduced. Mullins, Aniol, Boyd, Page, and Chaney (2002) also found respite care lowered psychological distress of parents of children with developmental disabilities. Specifically in married parents of children with ASD, Harper, Dyches, Harper, Roper, and South (2013) found even one hour of respite care a week significantly lowered mother and father stress levels.

Barriers to respite care. When parents of children with disabilities were asked about caring for their own health, one reported barrier was lack of respite time (Murphy et al., 2007). These parents used respite time to care for other individuals in their family rather than use it to care for themselves. Perhaps parents of multiple children have a greater need for respite care in order to care for themselves as well as their additional children. In a recent study of 15 families of children with ASD, it was reported that all of the families express a need for respite care, but that they find the services inaccessible (Hodgetts, Nicholas, & Zwaigenbaum, 2013). Although

respite care is considered beneficial to families of children with disabilities, the inaccessibility to these services may result in greater stress on these families.

Conclusion

Single mothers of children with ASD experience multiple stressors, such as finances, employment, and relationship with biological father, which may increase their levels of depression, their reports of daily uplifts and hassles, and caregiver burden. Behavior of their child with ASD, financial stress, job stress, personal relationship stress, and stress related to caring for their child may create a pileup of stressors, creating a crisis event for these single mothers of children with ASD. It may be that a break from caring for their child with ASD would alleviate some of that stress and lessen levels of depression. Respite care has been found to reduce stress and increase reported daily uplifts for married mothers of children with ASD and it is important to understand how respite care would impact single mothers' levels of depression, stress, and daily uplifts.

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APPENDIX B: Consent Form and Recruitment Materials

Single Parenting a Child with Autism Spectrum Disorder Consent to be a Research Subject

Introduction

This research study is being conducted by Ruthann Christensen, a School Psychology graduate student at Brigham Young University. The purpose of this study is to determine how the amount of respite care is related to level of emotional health, daily uplifts/hassles, and caregiver burden of single mothers who have children diagnosed with autism spectrum disorder. You are invited to participate because you are a single mother and have a child with autism spectrum disorder (ASD).

Procedures

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

- You will receive a questionnaire by your choice of postal mail, e-mail, or Internet link.
- The questionnaire will include questions about you such as your age, relationship status, household income, family size; the amount of respite care you receive for your child with ASD, daily uplifts and hassles, caregiver burden, and your emotional well-being.
- It will take 45-60 minutes to complete the questionnaires and you may complete these in your home.
- You will return your questionnaires 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 emotional health. Answering honestly may aid other single mothers of children with ASD.

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 single mothers who are caring for a child with an Autism Spectrum Disorder.

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 the questionnaire is 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 Ruthann Christensen at (801) 850-8404 or at ruthann.grawe@gmail.com or Tina Dyches, Ed.D. at (801) 422-5045, tina_dyches@byu.edu.

Questions about your Rights as a Research Participant

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.

Signature: _____ Date: _____

Consent for Organizations

I, _____ (name and title), hereby grant Brigham Young University researchers, Ruthann Christensen and Tina Dyches, permission to advertise their research regarding single mothers of children with autism spectrum disorder 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 ASD,
- Printing the attached flyer and posting it in our building,
- Printing the attached flyer and sending it home to single parents of children with ASD, 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

Recruitment Email

Dear [insert name],

Recent research has indicated respite care can be beneficial for families raising children with autism spectrum disorder (ASD), 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 single mothers of children with ASD. Researchers at Brigham Young University are studying the relationships between respite care and family functioning of single mothers of children with ASD. 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 ASD,
- Printing the attached flyer and posting it in your building,
- Printing the attached flyer and sending it home to single parents of children with ASD, 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,

Ruthann Christensen
School Psychology Graduate Student

Tina Dyches, Ed.D.
Associate Professor, Department of Counseling Psychology and Special Education

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 single mothers of children with autism spectrum disorders 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: https://byu.qualtrics.com/SE/?SID=SV_9Y2YFbmRuhUNNXe or contact Dr. Tina Dyches at tina_dyches@byu.edu or (801) 422-5045.

PARTICIPANTS NEEDED FOR
RESEARCH IN

Single Mothers of Children with
Autism Spectrum Disorders



We are looking for volunteers to take part in a study regarding respite care and family functioning in single mothers of children with autism spectrum disorders.

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: Instruments

Demographic Questions

1. What is your current relationship status?

- I am a single mother (separated, divorced, or widowed) living with my child(ren) with Autism Spectrum Disorders.
- I am a single mother (never married) living with my child(ren) with Autism Spectrum Disorders.
- *I am a single mother (separated, divorced, or never married) living with my child(ren) with Autism Spectrum Disorders AND another adult (grandparent, parent, significant other, friend).

* If this applies to you, please do not continue since the study requires single, non-cohabitating mothers with a child with Autism Spectrum Disorder.

2. What is your current age in years? _____

3. What is your ethnicity and race?

<input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> NOT Hispanic or Latino Race	<input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Black or African American <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> White <input type="checkbox"/> Other (list)
---	--

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

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

6. 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., PhD, MD, JD)

7. What is your gross annual household income?

- | | |
|---|---|
| <input type="checkbox"/> Less than \$7,000 | <input type="checkbox"/> \$80,001 to \$95,000 |
| <input type="checkbox"/> \$7,001 to \$16,000 | <input type="checkbox"/> \$95,001 to \$110,000 |
| <input type="checkbox"/> \$15,001 to \$25,000 | <input type="checkbox"/> \$110,001 to \$130,000 |
| <input type="checkbox"/> \$25,001 to \$50,000 | <input type="checkbox"/> \$130,001 to \$150,000 |
| <input type="checkbox"/> \$50,001 to \$65,000 | <input type="checkbox"/> over \$150,000 |
| <input type="checkbox"/> \$65,001 to \$80,000 | |

8. Do you have Sole or Joint custody of your child(ren)?

- | Legal
(right to make important
decisions about the children) | Physical
(where the children live) | N/A |
|---|---|--------------------------|
| <input type="checkbox"/> Sole | <input type="checkbox"/> Sole | <input type="checkbox"/> |
| <input type="checkbox"/> Joint | <input type="checkbox"/> Joint | <input type="checkbox"/> |
| <input type="checkbox"/> Other _____ | <input type="checkbox"/> Other _____ | <input type="checkbox"/> |

9. Do you receive child support payments from your child(ren)'s other parent?

- Yes, monthly (or in one annual lump sum)
- Yes, occasionally (a few times per year)
- Yes, rarely (once per year or less)
- No

10. If yes, how much do you receive in monthly child support?

- None
- Between \$1 - \$100 per month
- Between \$101 - \$200 per month
- Between \$201 - \$300 per month
- Between \$301 - \$400 per month
- Between \$401 - \$500 per month
- Between \$501 - \$600 per month
- Between \$601 - \$700 per month
- Between \$701 - \$800 per month
- More than \$800 per month

11. What other types of financial support do you receive from your child(ren)'s other parent?

- None
- Medical expenses (e.g., health insurance, out-of-pocket medical or dental expenses, speech therapy, behavioral therapy)
- Childcare expenses
- Educational expenses (e.g., tuition, fees)
- Other: List _____

10. Do you currently qualify to have your child(ren) receive free or reduced price meals at school?

- No.
- Our family qualifies for free meals.
- Our family qualifies for reduced price meals.
- Not Applicable (e.g., My child is not attending school where free or reduced meals are provided.)

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	1. Your children	0	1	2	3
0	1	2	5	2. Your parents or parents in-law	0	1	2	3
0	1	2	3	3. Your ex-significant other	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

0	1	2	3	29. Exercise(s)	0	1	2	3
0	1	2	3	30. Your medical care	0	1	2	3
0	1	2	3	31. Your health	0	1	2	3
0	1	2	3	32. Your physical abilities	0	1	2	3
0	1	2	3	33. The weather	0	1	2	3
0	1	2	3	34. News events	0	1	2	3
0	1	2	3	35. Your environment (quality of air, noise level, greenery, etc.)	0	1	2	3
0	1	2	3	36. Political or social issues	0	1	2	3
0	1	2	3	37. Your neighborhood	0	1	2	3
0	1	2	3	38. Conserving (gas, electricity, water, gasoline, etc.)	0	1	2	3
0	1	2	3	39. Pets	0	1	2	3
0	1	2	3	40. Cooking	0	1	2	3
0	1	2	3	41. Housework	0	1	2	3
0	1	2	3	42. Home repairs	0	1	2	3
0	1	2	3	43. Yard work	0	1	2	3
0	1	2	3	44. Car maintenance	0	1	2	3
0	1	2	3	45. Taking care of paperwork (paying bills, filling out forms, etc.)	0	1	2	3
0	1	2	3	46. Home entertainment (TV, music, reading, etc.)	0	1	2	3
0	1	2	3	47. Amount of free time	0	1	2	3
0	1	2	3	48. Recreation and entertainment outside the home (movies, sports, eating out walking, etc.)	0	1	2	3
0	1	2	3	49. Eating (at home)	0	1	2	3
0	1	2	3	50. Church or community organizations	0	1	2	3
0	1	2	3	51. Legal matters	0	1	2	3
0	1	2	3	52. Being organized	0	1	2	3
0	1	2	3	53. Social commitments	0	1	2	3
0	1	2	3	54. Dating partner	0	1	2	3

If you have an additional child (children) with an Autism Spectrum Disorder, please complete the question below for your second child. IF NOT, please skip to Question #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 Which 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 (children) with an Autism Spectrum Disorder, please complete the question below for your third child. IF NOT, please skip to Question #2.

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

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

Caregiver Burden Instrument

Below is a list of typical everyday events that parents may encounter: Thinking of what it takes to raise all the children in your family, for each item, circle how frequently this generally occurs and then how much of a hassle you find it.

	<u>How Frequently</u>				<u>How Much of a Hassle</u>			
	1- Rarely	2- Sometimes	3- A Lot	4- Constantly	1- No hassle	2- A little hassle	3- Medium hassle	4- Big hassle
1. Feeling that my time is not my own. Care of my children interferes with housework, employment, family life, hobbies, or other outside interests, etc.	1	2	3	4	1	2	3	4
2. Feeling overwhelmed at all there is to do in caring for my children.	1	2	3	4	1	2	3	4
3. Feeling financial strain involved in caring for my children.	1	2	3	4	1	2	3	4
4. Feeling that I need to change my plans in order to fulfill my children's needs.	1	2	3	4	1	2	3	4
5. Feeling that my children are a source of joy to me.	1	2	3	4	1	2	3	4
6. Feeling that I don't have time to maintain my physical health due to caring for my children (e.g., exercise, eat right).	1	2	3	4	1	2	3	4
7. Feeling that rearing my children brings me closer to my spouse (or ex-spouse where applicable.)	1	2	3	4	1	2	3	4
8. Feeling that my children provide stimulation and learning for me.	1	2	3	4	1	2	3	4
9. Feeling emotionally drained due to caring for my children-- emotionally frazzled and worn out.	1	2	3	4	1	2	3	4
10. Feeling that rearing my children creates more conflict and arguments with significant others (eg., my parents, friends, etc.)	1	2	3	4	1	2	3	4

	<u>How Frequently</u>				<u>How Much of a Hassle</u>			
	1- Rarely	2- Sometimes	3- A Lot	4- Constantly	1- No hassle	2- A little hassle	3- Medium hassle	4- Big hassle
11. Feelings of isolation—No one understands what I am going through in raising my children.	1	2	3	4	1	2	3	4
12. Feeling that my children teach me wonderful and worthwhile things.	1	2	3	4	1	2	3	4
13. Feeling that my children get along with each other well (in cases where there is more than one child).	1	2	3	4	1	2	3	4
14. Experiencing loss of sleep due to meeting my children's needs.	1	2	3	4	1	2	3	4
15. Feeling physically drained by caring for my children-- (e.g., bathing, feeding, cleaning, etc.)	1	2	3	4	1	2	3	4
16. Feeling that caring for my children is an inconvenience.	1	2	3	4	1	2	3	4
17. Feeling that my personal growth is enhanced because of caring for my children.	1	2	3	4	1	2	3	4
18. Feeling that rearing my children creates more conflicts with my spouse. (or ex-spouse where applicable).	1	2	3	4	1	2	3	4
19. Feeling that rearing my children brings me closer to significant others (e.g., my parents, friends, etc.).	1	2	3	4	1	2	3	4
20. Feeling that my children don't get along with each other well (in cases where there is more than one child)	1	2	3	4	1	2	3	4

Center for Epidemiologic Studies Depression Scale

Below is a list of some ways you may have felt or behaved. Please indicate how often you have felt this way during the last week by checking the appropriate space. Please only provide one answer to each question.

During the past week:	<i>Rarely</i> or none of the time (<1 day)	<i>Occasionally</i> or a moderate amount of the time (3-4 days)	<i>Some</i> or a little of the time (1-2 days)	<i>Most</i> or all of the time (5-7 days)
1. I was bothered by things that don't usually bother me.	1	2	3	4
2. I did not feel like eating; my appetite was poor.	1	2	3	4
3. I felt that I could not shake off the blues even with the help of my family or friends.	1	2	3	4
4. I felt that I was just as good as other people.	1	2	3	4
5. I had trouble keeping my mind on what I was doing.	1	2	3	4
6. I felt depressed.	1	2	3	4
7. I felt everything I did was an effort.	1	2	3	4
8. I felt hopeful about the future.	1	2	3	4
9. I thought my life had been a failure.	1	2	3	4
10. I felt fearful.	1	2	3	4
11. My sleep was restless.	1	2	3	4
12. I was happy.	1	2	3	4
13. I talked less than usual.	1	2	3	4
14. I felt lonely.	1	2	3	4
15. People were unfriendly.	1	2	3	4
16. I enjoyed life.	1	2	3	4
17. I had crying spells.	1	2	3	4
18. I felt sad.	1	2	3	4
19. I felt that people disliked me.	1	2	3	4
20. I could not get "going".	1	2	3	4