2020

Family Satisfaction As A Function Of Cohesion, Flexibility, And Coping Among Parents Of Children With Down Syndrome

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FAMILY SATISFACTION AS A FUNCTION OF COHESION, FLEXIBILITY, AND COPING AMONG PARENTS OF CHILDREN WITH DOWN SYNDROME

by

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A Dissertation

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Education

Major: Counseling

The University of Memphis

May 2020

Abstract

When a child with Down syndrome is born in to a family the special needs of the child, the birth and the reactions of the family members can cause stress to the family system. The family system's characteristics affect how well the family can adjusts to these stressors. Understanding the relationship of the family system's characteristics to stress adaptation can help counselors aid these families as they implement these changes. The objectives of this study were to determine (a) how balanced family cohesion and balanced family flexibility relate to family satisfaction for families with a child with Down syndrome, and (b) how the family coping skills of seeking support from friends and family, accepting stressful events as inevitable and believing they are solvable, attending spiritual services or consulting spiritual leaders, seeking information from professionals about family difficulties, and hoping that problems will eventually resolve themself relate to family satisfaction in this same population. Eighty parents of children with Down syndrome whose child currently resided with the parent completed surveys online. Participating parents were recruited through various online Down syndrome support and advocacy groups. Family satisfaction, family flexibility, and family cohesion were measured using the FACES-IV survey. Family coping skills were assessed using the F-COPES survey. Linear regression analysis indicated that cohesion ratio ($p < .001$) and flexibility ratio ($p = .02$) were significant predictors of family satisfaction. Of the five coping subscales only the subscales of reframing ($p < .001$) and passive appraisal ($p < .001$) were significant predictors of family satisfaction. Information from this study is then compared to results from other studies. Counseling implications for addressing family satisfaction in terms of the relevant coping skills are presented.

Keywords: family flexibility, family cohesion, family coping, family adaptation, family satisfaction, families of children with special needs, families of children with Down syndrome.

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Introduction

Throughout a family's development and growth there are numerous opportunities for stress and crisis. One of the most significant events is the birth of a child. When the child has special needs there are additional stresses (Marshak & Prezant, 2007). While there are a number of medical and behavioral conditions under the category of special needs, one of the most common is having a child with Down syndrome. Down syndrome occurs in approximately one in 737 births in the United States (Parker et al., 2010).

Research provides support that the introduction of a child with Down syndrome into the family system increases stressors to various components of the family system. These stressors include the special care needs of the child, including unusual sleep schedules interrupted by necessary medical care, administering extra medications to address the myriad physical ailments, and keeping doctors' appointments for specialists as well as typical well-baby visits. (Marchal et al., 2013; Roach, 1999). In order to manage these stressors parents must reduce demands, reallocate resources, attempt to have some personal time and maintain family connectedness while dealing with feelings of self-blame, chronic sorrow, incompetence, and depression (Abery, 2006; Damrosch & Perry, 1998; Hauser-Cram et al., 1999; Marchal et al., 2013; Roach et al., 1999). Family dynamics heavily influence a family's ability to adapt to the changes associated with the birth of a child with special needs (Marshak & Prezant, 2007). Olson (2011) posited that a family's level of flexibility and cohesion were important in understanding the family's ability to adjust to family stressors and experience family satisfaction. While there is research investigating the impact of a number of family stressors including sibling relations (Cuskelly et al., 1998), the child temperament (Stoneman, 2007), parenting styles (Phillips et al., 2017), and

the availability of services and supports (Marshall et al., 2015), currently there are no studies investigating the relationship between family cohesion and flexibility and family coping strategies and family satisfaction for families experiencing the birth of a child with Down syndrome. The purpose of this study is to investigate the relationship between family cohesion and family flexibility on family satisfaction and the relationship between family coping mechanisms and family satisfaction for parents of children with Down syndrome.

Literature Review

The birth of a child with Down is a stressful life event for a family. Research provides support for the assertion that family cohesion and flexibility and family coping mechanisms are important in determining the family's ability to feel happy and fulfilled with each other. This section discusses (a) the prevalence and symptoms associated with Down syndrome, (b) the family stressors associated with the birth of a child with Down syndrome, (c) the theoretical framework for understanding the relationship between the variables investigated, and (d) the extant research on family cohesion, family flexibility, and family coping for families with a child with Down syndrome.

Down syndrome is a genetic abnormality resulting from the presence of a third copy of chromosome 21 that occurs in about one in 737 births (World Health Organization, 2016. Their conditions range in severity from mild to life-threatening (World Health Organization, 2016) and may require intensive surgical and medical management (Cleves et al., 2007). Down syndrome is associated with a number of physical and cognitive differences including low muscle tone, lax joints, thyroid issues, hearing problems, increased risk of leukemia, respiratory issues, vision problems, congenital heart malformations, gastrointestinal disorders, intellectual disability and

Alzheimer's (Booth & Vander, 2011; McGrath et al., 2011; Van Riper & Cohen, 2001; World Health Organization, 2016).

The breadth and severity of Down syndrome symptomology and the increased need for parental attention and resources cause stressors to the family system. Stressors can begin engaging the family or couple's coping process during the prenatal period, affecting both internal family dynamics and the family's dynamics with society. The perinatal stage may be characterized by feelings of powerlessness. Whether the pregnancy is relatively routine or complicated, most births take place in medical facilities where parents are submissive to medical authorities. Additionally, children with special needs are often in need of immediate medical attention away from the parents, leaving the parents to worry about their child and their parental roles instead of having the initial bonding period with the baby. Once at home, the child may need special home medical procedures or frequent hospital visits. As the child grows older families may grieve missing developmental milestones (Seligman & Darling, 2009).

The following research shows that frequent family adjustments are necessary and common. Families will face a pile-up of short-term stressors and long-term stressors, especially at times of major developmental changes for the child with Down syndrome (Abery, 2006). An example of this would be the pile-up of completing homework assignments, while planning for post-educational life, during the child's transition through adolescence. Hodapp et al. (2003) found that as the level of the child's maladaptive behavior increased, the parents experienced increased child-related stress; therefore, requiring adjustment to adapt the child's behavior to be acceptable. These stressors can affect the family members in a number of ways. Some parents of children with Down syndrome report chronic sorrow, self-blame, and expressions of negative affect as they adjust to the birth of their child (Damrosch & Perry, 1989). The need to maintain a

positive attitude has been identified as beneficial to parents of children with Down syndrome (Nelson-Goff et al., 2016). Some parents of children with Down syndrome express feelings of uncertainty for themselves and their child (Cless et al., 2018; Truitt et al., 2012). For some parents, accepting that their child has Down syndrome and is not neurotypical can be stressful (Nelson-Goff et al., 2016). Roach et al. (1999) reported that some parents found it difficult to establish feelings of attachment to the child and to cope with their child's behavioral difficulties.

The stressors also affect the parents' relationship with each other. Roach et al. (1999) found this to include role restriction in the home (i.e. lack of options and flexibility) and lack of available spousal support. For some parents the birth of a child with Down syndrome negatively affected their perceived marital quality (Norton et al., 2016). Van Riper (2007) reported that family problem-solving communication was positively associated with adaptation to having a child with Down syndrome. Having a child with Down syndrome can also cause stress between spouses related to restrictions imposed on the family's activities (Hornby, 1995).

The Resiliency Model of Family Adjustment and Adaptation provides a model that assists in understanding the process of adjustment as the family attempts to manage these stressors (McCubbin et al., 1997). The Resiliency Model explains a family's efforts to manage and resolve family stressors focusing on the family's behavioral patterns and skills that allow the family to recover from a stressor. The model is based on five assumptions about family life: (a) stressors are a natural and predictable part of the family life cycle, (b) families acquire tools and skills that assist in adapting to stressors, (c) families develop tools for dealing with unexpected stressors following family crises and major changes, (d) families use and contribute to community relationships and resources, and (e) when stressful situations demand changes, the family applies its tools to restore stability. The change process of restoring stability to the family

is called adaptation. The adaptation may be successful ("bonadaptation") or unsuccessful (maladaptation) (McCubbin et al., 1997). When a family experiences a stressor, the family's vulnerability to resolving the stressor is related to the interpersonal and organizational conditions of the family system including the accumulation of demands (even normative changes) on the family unit (McCubbin et al., 1997).

Four family factors govern the family's attempts to adapt to the stressors. First, established patterns of functioning are sets of attributes or behaviors that define how the family system typically operates or behaves, providing a predictable and discernible pattern of family functioning (McCubbin et al., 1997). Second, family resources include social support, economic stability, cohesiveness, flexibility, hardiness, shared spiritual beliefs, open communication, traditions, celebrations, routines, and organization (McCubbin et al., 1997). Third, family appraisal of the stressor is how a family defines the seriousness of a stressor (McCubbin et al., 1997). Finally, problem-solving and coping are governed by the family's ability to frame stressors into manageable pieces, identify alternative courses of action, initiate steps to resolve issues, and create patterns of problem-solving communication to maintain or restore family harmony and balance (McCubbin et al., 1997). If the family is able to maintain or restore its well-being it has achieved bonadaptation.

In the current study, the birth of a child with Down syndrome is considered a family stressor. The study examines the impact of (a) two types of family resources (cohesion and flexibility) and (b) family coping skills on family satisfaction. With respect to the current study family satisfaction is considered to be bonadaptation.

Family Cohesion

Family cohesion is "the emotional bonding that family members have toward one another" (Olson, 2000, p. 145). A healthy family seeks to balance the separateness or independence of the members with family togetherness. Families who assess as separated or connected are typically healthy families, while disengaged or enmeshed families are more likely to experience dysfunctions. Disengaged families have little attachment or commitment to their families, with individuals who are always doing as they please. Separated families demonstrate a tendency or willingness to act independently of other family members, although not in all cases, or to purposely exclude all others. Connected families will favor including other family members in decisions and activities but will also act independently as necessary. Enmeshed families have too much consensus and too little independence. Separated and connected families are considered balanced. While balanced families (separated and connected) are more able to adjust to stressors, unbalanced families (disengaged and enmeshed) have a more difficult time adjusting to stressors.

Studying the stressor of adopting a child from the Soviet Union, McGuinness and Pallansch (2000) found that higher family cohesion was associated with higher levels of the child's competence and effectiveness at home. McGlone et al., (2002) found that adoptive parents of children with special needs reported parental stress scores inversely related to family cohesion and family adjustment. In a study of mothers of children with developmental disabilities, most with Down syndrome, mothers with non-cohesive families and low levels of maternal strength of cohesion reported higher levels of stress and negative mood, greater vulnerability to personal distress and depression, and an increased need for support (Margalit et

al., 2006). Finally, higher family cohesion was found to be a buffer against generalized anxiety disorder in Latina Americans (Ai et al., 2014).

Family Flexibility

Family flexibility is "the amount of change in its leadership, role relationships, and relationship rules" (Olson, 2000, p. 147). The focus of family flexibility is the balance of stability and change. The four levels of family flexibility are rigid, structured, flexible, and chaotic. Families who assess as structured or flexible are typically healthy families, while rigid or chaotic families are more likely to experience dysfunctions. It is typical of rigid families to have one individual who is in charge and highly controlling. There are limited negotiations and the leader imposes decisions. Roles are strictly defined, and rules do not change. Structured families' members have delegated roles and general rules, but those are changeable and amendable as the situation necessitates. Flexible families' roles are less defined and may be in constant flux, but to no one's alarm or discomfort. In a chaotic family, leadership is erratic and limited. Decisions are impulsive and poorly thought-out. Roles within the family are unclear and fluctuate unpredictably. While flexible and structured families are better able to handle stressors, rigid and chaotic families have a more difficult time managing stressors.

In a study of infants with disabilities and their families, lower levels of family flexibility were associated with an increase in negative effects on self-mastery, financial strain, feelings of distress, and family/social strain on the family (Shonkoff et al., 1992). In a study of stepfamilies, low to moderate levels of cohesion and moderate to high levels of flexibility were associated with stepfamily satisfaction. However, stepfamily cohesion was lower than that of nuclear families in the same life cycle stage, while flexibility was higher (Pill, 1990). In a study of families with a school-age child with autism, positive family flexibility was related to a

substantial amount of the variance in higher family functioning and lower parental distress (Manning et al., 2011).

Family Coping

Coping is comprised of the behavioral efforts by which an individual family member, or the family functioning as a whole, attempts to reduce or manage a stressor's demand on the family system. Coping patterns occur as the coping behaviors become generalized ways of responding to different kinds of stressful situations, regardless of the specific circumstances (McCubbin et al., 1997).

McCubbin et al. (1997) identified five methods families use to manage stressors: (a) acquiring social support includes sharing difficulties with relatives, seeking encouragement and support from friends, and asking neighbors for favors and assistance and is associated with emotional and physical well-being (Becofsky et al., 2015; Heo, 2014; McCubbin et al., 1997; White et al., 2009); (b) reframing is defined as knowing you have the power to solve major problems, facing problems head-on and trying to get a solution right away, and accepting stressful events as a fact of life and is positively associated with improved parental role satisfaction, improved levels of hope and lower levels for depression (Geffken et al., 2006; McCubbin et al., 1997; Podolski & Nigg, 2001); (c) seeking spiritual support includes behaviors such as attending church services and seeking advice from a minister (McCubbin et al., 1997) and is associated with less depression and anxiety, more marital commitment (Lucero et al., 2013) and increased family communication (Prouty et al., 2016); (d) mobilizing family support involves seeking information and advice from professionals related to family difficulties (McCubbin et al., 1997). Among families of children with developmental disabilities, Carroll (2014) reported that family support was positively related to optimism, which was correlated

with higher positive affect and life satisfaction, and lower levels of depression and parenting stress; and (e) passive appraisal, considered a hindrance to healthy coping. Coping behaviors associated with passive appraisal include knowing luck plays a big part in how well we are able to solve family problems and believing that if we wait long enough the problem will go away (McCubbin et al., 1997). Atkinson et al. (1995) found that among mothers of children with Down syndrome, passive appraisal was negatively related to their behavioral sensitivity toward their child. In families with a child with a disability, Lustig (2002) found that better family adjustment was related to less use of passive appraisal and more use of reframing. Smith et al. (2015) showed that higher passive appraisal coping led to increased caregiver distress.

The extant literature provides support for the assertion that the coping strategy utilized by the family impacts their ability to manage stressors. Dunst et al. (1986) found that family stress and coping were factors associated with development in children with special needs. Children in families with larger social support/coping networks made significantly more developmental gains, and parents of these children reported better emotional and physical health. Van Riper (2007), in a study of families with Down syndrome, found that three family variables were significantly associated with family coping: family demands, family resources, and family problem-solving communication. Truitt et al. (2012), studying caregivers of children with Down syndrome, found that while hope was positively associated with adaptation, uncertainty of how to achieve the goals they had hoped for their child was negatively associated with adaptation.

The birth of a child with Down syndrome can be considered a family stressor. Presented with this stressor, the family seeks to manage the stressor and achieve adaptation. While research provides support that, in general, family cohesion and flexibility and family coping strategies are important factors in determining whether the family is able to achieve bonadaptation rather than

maladaptation, currently there are no studies investigating the impact of family cohesion and flexibility and family coping strategies on adaptation for families with a son or daughter with Down syndrome. The current study addresses this deficit in the extant literature. Specifically, the following research questions are addressed:

1. How do balanced family cohesion and balanced family flexibility relate to family satisfaction for families with a child with Down syndrome?
2. How do the five family coping subscales (acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal) relate to family satisfaction for families with a child with Down syndrome?

Methods

Participants

Study participants were required to be over eighteen years old and either parents or guardians of a child with Down syndrome. The child with Down syndrome had to have been currently residing with the parents or guardians. The age of the child was not limited provided they still resided with the parents or guardian. The demographics requested of the study participants included: age, gender, marital status, relationship to the child with Down syndrome, race/ethnic identification, education level, household income, number of dependents in the household, and total number of people in the household.

Participants ranged in age from 28 to 65 (M = 46.3; SD = 9.5). Most participants identified as females (90%; *n* = 72), and 10% (*n* = 8) identified as males. The majority of respondents reported being married (85%; *n* = 68), the second highest response was divorced (12%; *n* = 9), while responses of single (1%; *n* = 1) and widowed (1%; *n* = 1) were rare, and one participant declined to answer (1%; *n* = 1). All of the respondents were parents (100%; *n* = 80).

Racial/ethnic data indicates that 91.3% (*n* = 73) were White, the remainder identifying as African Americans (3.8%; *n* = 3), two or more races (2.5%; *n* = 2), Asian/Pacific Islander (1.3%, *n* = 1), and Hispanic/Latino (1.3%, *n* = 1). Response rates were equal for survey-takers with graduate/professional degrees (40%; *n* = 32) and bachelor's degrees (40%; *n* = 32), followed by junior college/vocational school (15%; *n* = 12), high school degree or GED (3.8%; *n* = 3), and one no response. Pre - tax income levels for most respondents were high: +$100,000 (50%; *n* = 40), $80,000–$99,999 (16.3%; n = 13), $60,000–$79,999 (11.3%; n = 9), $40,000–$59,999 (11.3%; *n* = 9), $20,000–$39,999 (7.5%; *n* = 6), and three no responses. The number of dependents in the household ranged from 0 to 15 (M = 2.6; SD = 1.9). The total number of people residing in the household ranged from 2 to 17 (M = 4.5; SD = 2).

Instruments

Family Adaptability and Cohesion Evaluation Scale IV–Family Satisfaction

The dependent variable for this study is family satisfaction and is defined as "as the degree to which family members feel happy and fulfilled with each other (Olson, 2010, p. 1)." It was assessed by Olson's (2011) FACES IV Family Satisfaction Scale (FSS). There are ten items that ask respondents to rank their satisfaction with specified items (e.g. the degree of closeness between family members). The scores are from 1 to 5, indicating Very Dissatisfied (a value of 1) to Extremely Satisfied (a value of 5). Cronbach's alpha reliability for the FSS is reported as .92. In this study an internal Cronbach's alpha reliability was found to be .89.

Family Adaptability and Cohesion Evaluation Scale IV

The Family Adaptability and Cohesion Evaluation Scale (FACES) IV survey includes measures of family cohesion and family flexibility (Olson, 2011). Participants are asked to rank their agreement with the survey's statements from 1 = Strongly Disagree to 5 = Strongly Agree.

The responses for each subscale item are summed to calculate the value for that subscale. Ratio scores are used for data analysis. The Flexibility ratio is calculated as follows: (balanced flexibility) / [(rigid + chaotic) / 2]. The Cohesion ratio is calculated as follows: (balanced cohesion) / [(enmeshed + disengaged) / 2].

Confirmatory factor analysis supports the six constructs measured by the FACES IV and discriminant analysis supported the ability of the scales to distinguish between families with and without problems (Olson, 2011). Cronbach's alpha reliability has been reported as follows: (a) Balanced Cohesion = .89, (b) Balanced Flexibility = .84, (c) Chaotic = .86, (d) Enmeshed = .77, (e) Rigid = .82, and (f) Disengaged = .87. Cronbach's alpha reliability coefficients for this study were found to be .55, .45, .81, .63, .58, and .65 respectively.

Family Crisis Oriented Personal Evaluation Scale

The Family Crisis Oriented Personal Evaluation Scale (F-COPES) assesses a family's approach to problem-solving and behavioral strategies (McCubbin et al., 1997, p. 455). It is based on the Resiliency Model of Family Adjustment and Adaptation. There are five subscales. The first subscale, acquiring social support, measures a family's ability to actively engage in acquiring support from relatives, friends, neighbors, and extended family. The second subscale, reframing, measures the family's capability to redefine stressful events in order to make them more manageable. The third subscale, seeking spiritual support, measures the family's ability to acquire spiritual support. The fourth subscale, mobilizing family to acquire and accept help, measures the ability of the family to seek out community resources and accept help from others. The fifth subscale, passive appraisal, measures the family's ability to accept problematic issues minimizing reactivity. There are thirty items on the survey that asks respondents to rank statements from 1 to 5, indicating Strongly Disagree = 1 to Strongly Agree = 5. The responses

are then summed to indicate the overall coping score. Cronbach's alpha reliability score for F-COPES is .86 overall. The subscales and their reliability scores are: acquiring social support .83, reframing .82, seeking spiritual support .80, mobilizing family to acquire and accept help .71, and passive appraisal .63. Subscale internal reliabilities for this study were estimated to be .86, .69, .88, .64, and .62 respectively.

Procedures

This study used a convenience sampling method. Participants were recruited by dissemination of an Internet link to the survey through various, nationwide, Down syndrome-associated groups (e.g., parent support organizations, Down syndrome research groups). These organizations posted the link to their webpages, social media outlets, and electronic newsletters. Participants filled out the surveys online using surveymonkey.com. They remain anonymous, and individual responses are held in confidence.

The Institutional Review Board at the University of Memphis approved the current study for ethical considerations before dissemination. The study was also approved by the appropriate authorities at the support organizations before posting to their websites or email distribution. Study participation was completely voluntary and did not impact the services or products received by the participants from the support organizations. Participants were informed that participation was voluntary, that the collected data would be confidential, and that they could withdraw from the study at any time without penalty.

Data Analysis

Descriptive statistics and demographics were summarized. IBM SPSS Statistics (Version 26) and G*Power (Version 3.1) analytical software were used to analyze the data. All linear regression assumptions for linearity, lack of outliers, normality of residuals, homoscedasticity,

and lack of multicollinearity were met. Multiple linear regressions were used to examine (1) the influence of family cohesion and flexibility on family satisfaction and (2) the influence of family coping subscales, specifically, acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal, on family satisfaction. Hypothesis testing used an alpha value of .05. Post hoc power analyses were performed. There were a total of four missing responses to any of the instruments' items. These missing data were ignored for purposes of analysis as they would not significantly change the results.

Results

It was noted that the alpha coefficients for the FACES-IV subscales of balanced cohesion, balanced flexibility, and rigid were below values found in previous research and below the generally acceptable value of .60 for use in statistical analysis. The following methods were used to determine if the responses were valid and to attempt to improve the Cronbach's alpha reliability. In order to determine if there were participants who completed the survey randomly, the data was examined for indications of participants providing answers without considering the questions (e.g., marking the first response to all questions). This examination produced no unusual response sets. In an effort to improve Cronbach's alpha reliability, individual subscale items were examined for their effect on alpha reliability. Using SPSS Item-Total Statistics matrixes, single problematic items were identified in the balanced cohesion and rigid subscales. Deleting these items resulted in alpha coefficients of .71 for the balanced cohesion subscale and .66 for rigid subscale. Analysis of the Item-Total Statistics matrix for the balanced flexibility subscale was evaluated through systematic reductions in the number of items. Eventually, the balanced flexibility subscale was reduced to one item to represent the subscale, "My family is able to adjust to change when necessary." The subscales of balanced cohesion, balanced

flexibility, and rigid were then scaled appropriately to calculate the cohesion ratio and flexibility ratio. The means, standard deviations, and correlations for cohesion ratio, flexibility ratio, coping subscales and family satisfaction measures are shown in Table 1.

Table 1

Correlations of the Dependent and Independent Variables

	Satisfaction	Cohesion	Flexibility	Social	Reframing	Spiritual	Family	Passive
Cohesion	.63**							
Flexibility	.49**	.48**						
Social	-.24*	.02	-.07					
Reframing	.47**	.35*	.51**	-.11				
Spiritual	-.05	.18	.16	.24*	-.04			
Family	-.19*	-.11	-.07	.47**	-.15	-.11		
Passive	.45**	.43**	.33*	-.05	.06	.10	-.08	
M	38.1	2.8	1.7	28.7	31.9	14.1	14.2	15.6
SD	5.6	0.7	0.3	6.7	3.5	4.6	3.0	2.8

Note. Satisfaction = family satisfaction; Cohesion = cohesion ratio; Flexibility = flexibility ratio; Social = acquiring social support; Spiritual = seeking spiritual support; Family = mobilizing family support; Passive = passive appraisal

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

Cohesion ratios and flexibility ratios were calculated from the FACES-IV subscales. A linear regression to evaluate the relationship of the cohesion ratio and flexibility ratio to family satisfaction was performed. Analysis showed that the over model was significant F (2, 75) = 29.29, $p < .001$, $R^2 = .44$, adjusted $R^2 = .42$. Post hoc power analysis was calculated at .87 for medium effect size of 0.15. The standard coefficients for the independent variables cohesion ratio and flexibility ratio were $\beta = .51$ ($p < .001$) and $\beta = .24$ ($p = .02$). A full description of the linear regression statistics is shown in Table 2.

Table 2

Regression Summary for Research Question 1

Variable	*B*	95% CI for *B*	*Beta*	Significance
Constant	20.73	[15.76, 25.70]		.000
Cohesion ratio	3.93	[2.42, 5.44]	.51	.000
Flexibility ratio	3.88	[.73, 7.03]	.24	.017
R^2	.44			
F	29.29			

To explore the second research question, a linear regression was conducted to determine if family satisfaction was significantly predicted by the coping scales of acquiring social support, reframing, seeking spiritual support, mobilizing family support, and passive appraisal. Analysis showed that the overall model was significant $F(5, 72) = 10.41$, $p < .001$, $R^2 = .42$, adjusted $R^2 = .38$. Post hoc power analysis was calculated at .73 for medium effect size of 0.15. Only two of

the subscales were significant predictors of family satisfaction: reframing and passive appraisal. The standard coefficient of the reframing subscale was $\beta = .42$ ($p < .001$). The standard coefficient of the passive appraisal subscale was $\beta = .42$ ($p < .001$). Complete regression summary for the significant predictors is shown in Table 3.

Table 3

Regression Summary for Research Question 2

Variable	*B*	95% CI for *B*	*Beta*	Significance
Constant	8.43	[-4.54, 21.40]		.199
Social	-.11	[-.29, .07]	-.14	.218
Reframing	.67	[.38, .97]	.42	.000
Spiritual	-.05	[-.28, .19]	-.04	.701
Family	-.05	[-.45, .35]	-.03	.804
Passive	.82	[.46, 1.17]	.42	.000
R^2	.42			
F	10.41			

Note. Satisfaction = family satisfaction; Social = acquiring social support; Spiritual = seeking spiritual support; Family = mobilizing family support; Passive = passive appraisal

Discussion

The first research question was concerned with the relationship of family cohesion and family flexibility to family satisfaction for families of with a child with Down syndrome. Family satisfaction is "the degree to which family members feel happy and fulfilled with each other"

(Olson, 2010, p. 1). Cohesion is related to the balance of bondedness and independence in the family and flexibility is related to the balance of change and stability (Olson, 2000). The results of this study indicate a positive relationship between family cohesion and family flexibility and family satisfaction. Past research has shown similar outcomes to the results of this research. McGlone et al. (2002), studying adoptive parents of special needs children found family flexibility and family cohesion were inversely related to parenting stress scores. Shonkoff et al. (1992) found that among families of infants with disabilities that families with lower levels of flexibility reported increases in negative effects on the family.

The second research question focused on the relationship between family coping (acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal) and family satisfaction for families with a child with Down syndrome. The results of this study indicated that higher levels of reframing and lower levels of passive appraisal contributed to higher family satisfaction. Reframing is concerned with how a family sees change, as positive or negative (McCubbin et al., 1997). The family may perceive the birth of a child with Down syndrome as either an opportunity for growth and learning or as a burden to the family. Passive appraisal examines a family's tendency to employ avoidance responses to stressors (McCubbin et al., 1997). For example, the family ignores the special health-care needs of the child in the belief that it will all work out without specific intervention.

The findings of this study in relation to the second research question are supported by past research. Darling et al. (2012) found that fathers of children with disabilities and fathers of neurotypical children both preferred coping skills of reframing and passive appraisal. Lustig's (2002) study indicated that less frequent use of passive appraisal and more frequent use of reframing were associated with better family adjustment among families of children with

developmental disabilities. Both of these studies used the F-COPES survey, and in both cases, the subscales of acquiring social support, seeking spiritual support, and mobilizing family to acquire and accept help were not found to be significantly related to their outcome variables.

Other studies have focused on each of the coping skills separately. Manning et al. (2011) found that among families of children with autism, reframing coping skills were strongly associated with better family adaptation. Minnes et al.'s (2015) study of parents of young children with developmental delays and disabilities found that reframing was positively related to gains in parent well-being. Parents of children with attention deficit hyperactivity disorder who reported higher use of reframing were more satisfied with their parental roles (Podolski & Nigg, 2001). Studying families of children with central nervous system impairment, Martin et al., (2004) found that these families used passive coping techniques more frequently than families of neurotypical children.

Counseling Implications

When counseling with a family who has a child with Down syndrome, counselors would be advised to examine the family's coping strategies, specifically reframing and avoiding passive appraisal, and family flexibility and cohesion to assess their impact on family satisfaction. Working with families on these characteristics is supported in various studies.

McGlone and colleagues' (2002) findings indicated parental-stress benefits from addressing family flexibility and cohesion. If families are assessed as rigid or chaotic, helping them to reduce the need for structure or find the benefit in adding structure should reduce parental stress. In the near term this may actually cause a temporary increase in family stress as the family members test new and unfamiliar experiences. However, in the long term, the family stress will likely decrease as the benefits of the new practices are realized. This could start by

introducing job charts to chaotic families or encouraging rigid families to expand their roles or delegate tasks to others. Marshak and Prezant (2007) looked at the case of parent/child enmeshment, which tends to happen more frequently with children with disabilities. In this case the parents, as a couple or as individual, do not have enough separation between the lives of the parents and the life of the child with disabilities. This may result in a weakening of the connection of the couple. A typical problem occurs when one parent is the daily care provider and the other parent works outside the home as the primary income provider. The individual who is away from home has trouble finding their role as caretaker and not just material provider. Counselors can address this by helping families communicate openly, and helping parents to evaluate and share their roles within the family.

Phillips et al. (2017), studying parenting styles of parents of children with Down syndrome, recommends that interventions focus on reducing stress related to parenting. These interventions included using less verbal hostility, reframing responses to the child in a more directive and less condemning manner, and less ignoring of misbehaviors, a passive appraisal action that allows misbehaviors to escalate to a higher level. Another method of reducing passive appraisal is through planned leisure activities. Wayne and Krishnagiri (2005) found that parents of children with Down syndrome benefited from leisure activities in reducing stress, while improving relaxation, rejuvenation, self-esteem, and self-fulfillment. One specific form of planned leisure activity that has shown positive results in parents of children with Down syndrome is the use of respite care (Norton et al., 2016). Taking active initiative to plan some time away from their child reduced stress and improved marital quality. Without actively seeking out time together, the bond between parents and lines of communication can break down.

Marshak and Prezant (2007) explored reframing techniques that can benefit the family of a child with special needs. For example, parents can view divergent parenting styles as complementary instead of conflicting. Setting realistic expectations with respect to parenting a child with special needs may also require reframing. Parents usually have great expectations for their child that are often not attainable when the child has Down syndrome. Reframing these expectations to goals that are achievable can assist in fostering family satisfaction. For example, while the goal of higher education for their child may be unattainable, parents can view success as their child's ability to live independently. Reframing is also a skill that can help in the redistribution and sharing of family responsibilities, such as seeing parental roles less as culturally a mother's or father's role than as the responsibility of the one who can best accomplish those tasks. Seligman and Darling (2009) present the bonadaptation function as normalization—a form of reframing. This reframing helps takes away the stigma of being "abnormal" and presents the family with the perspective of a different normal. Some aids to the normalization process are opportunity structures and support networks. Use of these two aids can help parents during the reframing process toward a different normal. Opportunity structures are those aids that are formally in place to help children with special needs and their families. By involving the family in opportunity structures, the family is exposed to other families who are experiencing or have experienced similar circumstances. Understanding that they are not alone and that there are resources for them to pull from can help the family with reframing their new life. In many instances, families have to make formal applications (i.e. active measures) to access these aids as well. An example of opportunity structures would be a government-funded program that gives financial support for medical and health-care supplies. Parents need to actively pursue these resources and be prepared for bureaucratic red tape, as opposed to taking a passive

approach or giving up at the first difficulty. Support networks are often less formal and relatively easy to join and benefit from, but it is up to the parents to actively seek them out and become engaged in their activities. As an example, many areas have Down syndrome associations that provide families of children with Down syndrome opportunities to network with each other. This networking can help the family to reframe the fact of having a child with Down syndrome in the family. These associations vary widely in membership, activities, and resources. And in most cases, the more active the family members are with the association, the more they will benefit from it.

Limitations

The following limitations are noted. First, there is a lack of diversity in the study's participants. In the current study most participants were White, female, and mothers of high socioeconomic status (SES) with moderate family sizes. Second, the study used voluntary participants who were recruited online. Consequently, participants needed access to the internet and had to be active in a Down syndrome organization. It is possible that the coping strategies employed by families active in Down syndrome organizations differs from those of other Down syndrome families. Third, coping is a culturally bound concept. The cultural norms and the presence of coping resources, such as access to services, may impact the types of coping strategies employed. Fourth, the study questionnaire asked only one family member to respond. In two-parent households the response of one parent does not necessarily reflect the views of their partner. Finally, the results may be specific to families with Down syndrome. Down syndrome is a relatively common occurrence among children with special needs. As a result, there tends to be a higher awareness of the disorder among the public. There also tend to be more resources available—organized, professional, or informal—for families adjusting to the birth of a

child with Down syndrome. Parents of children with other, less common special needs, may not respond similarly.

Future Research

The current study is a preliminary investigation into the relationship between coping strategies and family satisfaction for families with Down syndrome. Future research could focus on increasing participation of families from lower SES in order to find out if there are differences based on socioeconomic status. Including surveys with alternative languages would increase the likelihood that families whose first language is not English would complete the study. Finally, a qualitative research approach might provide insight into how these families cope with raising a child with Down syndrome.

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Appendix A

From: **Institutional Review Board** irb@memphis.edu
Subject: PRO-FY2019-241 - Modification: Approval - Modification
Date: November 27, 2019 at 8:24 AM
To: Daniel Charles Lustig (dlustig) dlustig@memphis.edu, Jeffrey Don Ricketts (jdrcktts) jdrcktts@memphis.edu

IR

Institutional Review Board
Division of Research and Innovation
Office of Research Compliance
University of Memphis
315 Admin Bldg
Memphis, TN 38152-3370

November 27, 2019

PI Name: Jeffrey Ricketts
Co-Investigators:
Advisor and/or Co-PI: Daniel Lustig
Submission Type: Modification
Title: Family Cohesion, Flexibility, and Coping Among Parents of Children with Down Syndrome
IRB ID **:** #PRO-FY2019-241
Level of Review: Exempt

Approval: November 27, 2019
Expiration: --*

The University of Memphis Institutional Review Board, FWA00006815, has reviewed your submission in accordance with all applicable statuses and regulations as well as ethical principles.

The modification is approved.

Approval of this project is given with the following obligations:

1. This IRB approval for modification has an expiration date, an approved renewal must be in effect to continue the project prior to that date. If approval is not obtained, the human subjects consent form(s) and recruiting material(s) are no longer valid and any research activities involving human subjects must stop.
2. When the project is finished a completion form must be submitted.
3. No change may be made in the approved protocol without prior board approval.
4. Human subjects training is required every 2 years and is to be kept current at citiprogram.org.

**Modifications do not extend the expiration of the original approval*

Thank you,
James P. Whelan, Ph.D.
Institutional Review Board Chair
The University of Memphis.

Appendix B

Requesting Distribution

To: “recipient”

I am hoping you can help me to complete my dissertation. My topic is family satisfaction among parents of children with Down syndrome. I am interested in the topic because my daughter has DS.

Would you consider posting a link to an online survey to your web-page, social media, or in a newsletter?

Here’s the link for your perusal:
https://www.surveymonkey.com/r/M8797MQ

If you have any questions or concerns you can contact me at the points below.

Thank you,
Jeff Ricketts
jdrcktts@memphis.edu
901-491-5363 cell/text

Appendix C

Recruitment Statement

In order to better understand the coping skills and their association to family satisfaction of a parent or guardian of a child with Down syndrome, we are conducting a research study investigating the relationship between parental coping strategies, family satisfaction, and their underlying components. We are asking for your participation in a research study investigating these characteristics. In order to participate you should be an adult (at least 18 years old) parent or guardian of a person with Down syndrome who currently resides in your home. The survey asks your opinion on 82 statements, and can be completed in 10 to 20 minutes.

Jeff Ricketts, University of Memphis

Daniel C. Lustig, Ph.D., University of Memphis

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Appendix D

Consent to Participate in a Research Study - Online

Parent/Guardian Coping Survey

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS RESEARCH?
You are being invited to take part in a research study about the relationship between family coping strategies and family satisfaction. You are being invited to take part in this research study because you are a parent or guardian who is at least 18 years old, and lives with someone who has Down syndrome. If you volunteer to take part in this study, you will be one of about 200 parents to do so.

WHO IS DOING THE STUDY?
The person in charge of this study is Jeff Ricketts (*Lead Investigator)* of The University of Memphis Department of Counseling, Educational Psychology and Research. Dr. Daniel Lustig is guiding him in this research.

WHAT IS THE PURPOSE OF THIS STUDY?
By doing this study, we hope to learn about the relationship between family coping and family satisfaction for parents or guardians of someone with Down syndrome.

ARE THERE REASONS WHY YOU SHOULD NOT TAKE PART IN THIS STUDY?
Only adult parents or guardians (18 years or older) who provide care for someone with Down syndrome should participate in this study.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?
The survey can be completed online using Survey Monkey. The survey should take about 10-20 minutes to complete.

WHAT WILL YOU BE ASKED TO DO?
You will be asked to complete two surveys and a demographic form.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?
To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?
Your willingness to take part, may, in the future, help society as a whole better understand the relationship between family coping and family satisfaction for parents or guardians of someone with Down syndrome.

DO YOU HAVE TO TAKE PART IN THE STUDY?
If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

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IF YOU DON'T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?
If you do not want to be in the study, there are no other choices except not to take part in the study.

WHAT WILL IT COST YOU TO PARTICIPATE?
There are no costs associated with taking part in the study.

WILL YOU RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?
At the end of the survey you will have the option of entering a drawing for one of two $100 Amazon.com gift certificates.

WHO WILL SEE THE INFORMATION THAT YOU GIVE?
We will make every effort to keep private all research records that identify you to the extent allowed by law. Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be personally identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private. This study is anonymous. That means that no one, not even members of the research team, will know that the information you give came from you.

CAN YOUR TAKING PART IN THE STUDY END EARLY?
If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study. The individuals conducting the study may need to withdraw you from the study. This may occur if you are not able to follow the directions they give you, or if they find that your being in the study is more risk than benefit to you.

ARE YOU PARTICIPATING OR CAN YOU PARTICIPATE IN ANOTHER RESEARCH STUDY AT THE SAME TIME AS PARTICIPATING IN THIS ONE?
You may take part in this study if you are currently involved in another research study.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS, CONCERNS, OR COMPLAINTS?
Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions, suggestions, concerns, or complaints about the study, you can contact the investigator, Jeff Ricketts at jdrcktts@memphis.edu or his advisor Daniel Lustig, Ph.D. at dlustig@memphis.edu. If you have any questions about your rights as a volunteer in this research, contact the Institutional Review Board staff at the University of Memphis at 901-678-2705.

Appendix E

FACES IV: Questionnaire

Directions to Family Members:

*Fill in the corresponding **number** in the space provided.*

1	2	3	4	5
Strongly Disagree	**Generally Disagree**	**Undecided**	**Generally Agree**	**Strongly Agree**

		Answers
1.	Family members are involved in each others lives.	
2.	Our family tries new ways of dealing with problems.	
3.	We get along better with people outside our family than inside.	
4.	We spend too much time together.	
5.	There are strict consequences for breaking the rules in our family.	
6.	We never seem to get organized in our family.	
7.	Family members feel very close to each other.	
8.	Parents equally share leadership in our family.	
9.	Family members seem to avoid contact with each other when at home.	
10.	Family members feel pressured to spend most free time together.	
11.	There are clear consequences when a family member does something wrong.	
12.	It is hard to know who the leader is in our family.	
13.	Family members are supportive of each other during difficult times.	
14.	Discipline is fair in our family.	
15.	Family members know very little about the friends of other family members.	
16.	Family members are too dependent on each other.	
17.	Our family has a rule for almost every possible situation.	
18.	Things do not get done in our family.	
19.	Family members consult other family members on important decisions.	
20.	My family is able to adjust to change when necessary.	
21.	Family members are on their own when there is a problem to be solved.	
22.	Family members have little need for friends outside the family.	
23.	Our family is highly organized.	
24.	It is unclear who is responsible for things (chores, activities) in our family.	
25.	Family members like to spend some of their free time with each other.	
26.	We shift household responsibilities from person to person.	
27.	Our family seldom does things together.	
28.	We feel too connected to each other.	

1	2	3	4	5
Strongly Disagree	**Generally Disagree**	**Undecided**	**Generally Agree**	**Strongly Agree**

		Answers
29.	Our family becomes frustrated when there is a change in our plans or routines.	
30.	There is no leadership in our family.	
31.	Although family members have individual interests, they still participant in family activities.	
32.	We have clear rules and roles in our family.	
33.	Family members seldom depend on each other.	
34.	We resent family members doing things outside the family.	
35.	It is important to follow the rules in our family.	
36.	Our family has a hard time keeping track of who does various household tasks.	
37.	Our family has a good balance of separateness and closeness.	
38.	When problems arise, we compromise.	
39.	Family members mainly operate independently.	
40.	Family members feel guilty if they want to spend time away from the family.	
41.	Once a decision is made, it is very difficult to modify that decision.	
42.	Our family feels hectic and disorganized.	

Family Satisfaction Scale

1	2	3	4	5
Very Dissatisfied	**Somewhat Dissatisfied**	**Generally Satisfied**	**Very Satisfied**	**Extremely Satisfied**

How satisfied are you with:

		Answers
1.	The degree of closeness between family members.	
2.	Your family's ability to cope with stress.	
3.	Your family's ability to be flexible.	
4.	Your family's ability to share positive experiences.	
5.	The quality of communication between family members.	
6.	Your family's ability to resolve conflicts.	
7.	The amount of time you spend together as a family.	
8.	The way problems are discussed.	
9.	The fairness of criticism in your family.	
10.	Family members concern for each other.	

Appendix F

F-COPES

Directions:

First, read the list of "Response Choices" one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you strongly agree; if the statement does not describe your response at all, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree then select a number 2, 3, or 4 to indicate how much you agree with the statement about your response.

Please circle a number (1, 2, 3, 4, or 5) to match your response to each statement. Thank you.

When we face problems or difficulties in our family, we respond by:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friends	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6. Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7. Knowing that we have the strength within our own family to solve our problems	1	2	3	4	5
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	1	2	3	4	5

When we face problems or difficulties in our family, we respond by:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
9. Seeking information and advice from the family doctor	1	2	3	4	5
10. Asking neighbors for favors and assistance	1	2	3	4	5
11. Facing the problems "head-on" and trying to get solutions right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5
14. Attending church services	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5
21. Seeking professional counseling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in church activities	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27. Seeking advice from a minister	1	2	3	4	5

When we face problems or difficulties in our family, we respond by:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5
29. Sharing problems with neighbors	1	2	3	4	5
30. Having faith in God	1	2	3	4	5

Appendix G

DEMOGRAPHIC INFORMATION

Please answer the questions as accurately as possible for the person taking the survey.

What is your age? _____

Are you ... ____ Female ___ Male _____ Other (specify)

Are you ....
____ Married ____Single ____Separated ___Divorced ____Widowed

Your relationship to the child with Down syndrome:
____ Parent _____ Foster Parent/Guardian _____ Grandparent

_____ Aunt/Uncle _____ Other (specify)

Your race/ ethnic group:
___ African-American ___ Asian/Pacific Islander ___ White

___Hispanic/Latino ___ Native American/Alaska Native ___ Two or More Races

____Other (specify)

Your education, highest level completed:
___ Did not finish high school or GED ___ High school degree or GED

___ junior college/vocational school ___ Bachelors ___ Graduate/professional degree

Your family income before taxes:
_____ **$**0-1$9,999 _____$20,000-$39,999 _____$40,000-$59,9999 _____$60,000-$79,999

_____$80,000-$99,999 _____$100,000

Number of dependents in your household? _____

Total number of people in your household? _____

"Is there anything you would like to add to the study information?" (100 character limit)
