HOPE, COPING, AND RELATIONSHIP QUALITY IN MOTHERS OF CHILDREN WITH DOWN SYNDROME

by

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Abstract

Parenting a child with Down syndrome may pose unique challenges for parents' relationship quality. Structural equation modeling was used with a sample of 351 mothers of children with Down syndrome to test if hope mediated the associated between various coping behaviors and relationship quality. Results indicated a greater degree of religious coping and internal coping were each significantly associated with more hope, whereas support seeking was not related with more hope. Higher hope was significantly associated with greater relationship quality. An indirect effect from both religious coping and internal coping to hope, and then hope to relationship quality was identified. Implications for family professionals and future research are discussed.

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Dedication

To my fiancé, Adam Cless, for your unconditional love and support. You are my go-to source for love, encouragement, strength, honesty, and coffee. Without your presence I would not be where I am today. I love you and am grateful for you every day of my life.

To my parents, siblings, and grandparents, who were there for me every step of the way. You have always supported my dreams and provided me with words of wisdom, encouragement, and challenges that have kept me on track as I work. You are all so important to me, and I could not imagine my life without your love and support.

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Chapter 1 - Introduction

Families of children with special needs are presented with unique issues that families with typically developing children may not experience. Families with a member who has special needs may encounter numerous challenges, including, but not limited to, developmental, medical, educational, social, and financial issues. Some strains described by these families may be coping with the diagnosis and the uncertainty of the condition, understanding what physical or developmental limitations may exist, identifying and accessing specialized services, dealing with chronic and sometimes severe health problems, engaging in community resources and support, and planning for the future (Flaherty & Masters Glidden, 2000; Glidden, Billings, & Jobe, 2006). In order to better understand these needs and challenges, researchers have studied stress and coping of families with a member with special needs, and specifically the experiences of parents, who are most often responsible for responding to these challenges and fulfilling the special needs of the child. What has been less often the focus of study, however, is the intimate partnership of parents of children with Down syndrome, and how this may be affected.

Down syndrome is a genetic condition in which a person is born with an extra copy of chromosome 21. It is the most common chromosomal disorder, occurring in 1 of about every 700 babies born in the United States (Parker et al., 2010). This condition is often characterized by physical and mental challenges that affect the person throughout his/her life. People with Down syndrome are at an increased risk for various health conditions such as sleep apnea, heart defects, thyroid disease, and anemia (Bull, 2011). Life expectancy for individuals with Down syndrome has dramatically increased over the last 50 years, increasing from an expected 10 years in 1960 to an expected 47 years in 2007 (Presson, Partyka, Jensen, Devine, Rasmussen, & McCabe,

2013). Parents of children with Down syndrome must respond to the needs of their children, which may require additional resources, such as time, finances, and social support.

Experiences of Parents

Literature regarding the experience of parents with a child with Down syndrome has largely focused on the stressors that parents may face and how this differs from stress in families without a child with special needs. Families with a child with Down syndrome have been shown to experience higher levels of stress and poorer coping than families with typically developing children (Sanders & Morgan, 1997). Additionally, behavioral difficulties in the child, which may be attributed to the special needs diagnosis, have also been linked with parents' depressive symptoms (Abbeduto et al., 2004).

Some literature compares parents of children with Down syndrome to parents of children who have a different disability. In a study by Siklos and Kerns (2006), both mothers and fathers of children with autism and parents of children with Down syndrome reported having a similar amount of needs, but differed in the type of supports needed. For example, parents of children with autism often reported needing help from various professionals to work with their child and their family, whereas parents of children with Down syndrome reported needing support from their child's school system, from community programs, and for their child to have opportunities to interact with friends. This finding is important as it highlights the differing needs of parents of children with Down syndrome and implies that different coping strategies and behaviors may also be beneficial to parents.

Related to outcomes of parent stress, some researchers have argued that parents of children with Down syndrome significantly differ from parents of children with other special needs diagnoses. In describing a phenomenon that has been termed as "The Down syndrome

advantage," Hodapp (2001) noted that "parents of children with Down syndrome seem to experience less stress than parents of children with autism, [and] other psychiatric conditions" (p. 326). More specifically, studies that have contributed to understanding the "Down syndrome advantage" have cited studies that demonstrate less overall stress in mothers, and warmer relationships between parents and children (Hodapp, 2007). Recent findings may shed more light on whether such an advantage exists for these parents. Various studies have found that when controlling for factors such as maternal age, income variance, and age and behavior of the child with Down syndrome, the "Down syndrome advantage" disappeared (Corrice & Glidden, 2009; Stoneman, 2007; Glidden, Grein, & Ludwig, 2014). These findings may contradict previous notions that parents of children with Down syndrome experience less stress or difficulty than those rearing a child with other disabilities. Taking this literature into account, it can be considered that raising a child with Down syndrome is presumably harder than raising a typically developing child. Additionally, the Down syndrome literature seems to have largely ignored variables that may help to shed light on the effect of having a child with Down syndrome on the parents' intimate partnership. Simply stated, the Down syndrome advantage, if present or absent in this population, does not fully speak to the effects of having a child with Down syndrome on the intimate partner relationship.

Relationship Quality

Relationship quality has been linked to a number of positive mental and physical health outcomes. Higher relationship quality has been associated with better physical health outcomes (Robles, Slatcher, Trombello, & McGinn, 2014; Umberson, Williams, Powers, Liu, & Needham, 2006). In populations of parents with special needs, relationship quality has been linked to favorable family outcomes such as lower parenting stress and fewer depressive symptoms

(Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Furthermore, in families with psychological distress, relationship quality has been shown to be helpful in remediating some of this stress (Davies & Cummings, 2006). Although there has been much evidence linking the importance of parent relationship quality to better outcomes for families with a child with special needs, less is known about what factors and processes are linked with relationship quality in this population.

Coping behaviors and levels of hope have been related to improvement in relationship quality (Snyder, 1994; Sullivan, 2002), however, this has not been specifically tested in a population of parents of children with Down syndrome. Identifying factors that have an effect on relationship quality, either negative or positive, may be important in understanding risk and protective factors for parents of children with Down syndrome. Thus, the purpose of the present study is to understand the relationship between coping, hope, and relationship quality in a sample of parents of children with Down syndrome.

Chapter 2 - Literature Review

Contextual Model of Family Stress

The contextual model of family stress (Boss, 2002) provides a guide for conceptualization of parents of children with a diagnosis of Down syndrome. This model, which is based on the original ABC-X model (see Hill, 1958), presents the stressor, *A*, as a factor that can contribute to stress in the family. In families with a child with special needs, this can be seen as the special needs or disability diagnosis. Resources, the *B* component, are defined as helpful coping behaviors available to the family on individual, family, and community levels. Resources can be internal or external, as well as concrete or abstract. Boss' contextual model of family stress extends perceptions, *C*, from the original model to include the concepts of socially constructed perceptions and meanings, which are descriptive of the parents' experience of having a child with Down syndrome in the family. Parents of children with Down syndrome may experience ambiguity in different settings, and at various times across the life span, as their child with special needs continues to grow and develop.

Boss (2002) additionally expands Hill's original ABC-X model to include the influence of contextual factors experienced by the family. The degree of family stress that is experienced depends upon the accumulation of both elements of external context and internal context. Elements of the external context may include cultural, historical, economic, developmental, and hereditary variables, whereas internal contexts may include structural, psychological, and philosophical factors (Boss, 2002). External contexts can be defined as elements that "begin from nature or from people outside the family" (Boss, 2006, p. 39). By its nature, a diagnosis of Down syndrome is a part of the family that is not controlled by the members of the family itself, but has externally come to affect the family system. This external contextual variable is

important to consider when considering family functioning in which there is a child with Down syndrome, as this gives the family unique context that affects their experiences together. This theoretical model puts the family's situation into context in order to better understand the family's experiences when encountering a disability or special needs diagnosis.

Application of the contextual model of family stress to relationship quality may be helpful in order to conceptualize how the stress of having a child with Down syndrome may affect a couple's relationship. The stressor event, the A component, remains the diagnosis and experience of being a parent of a child with special needs. The resources may be key in defining the perception of the marital relationship. In this model, coping behaviors and hope can be seen as resources, which may help define protective and/or risk factors for levels of relationship satisfaction. The aim of the present study was to examine if coping behaviors and hope may affect relationship quality of parents of children with Down syndrome.

The Couple Relationship

Research regarding the impact of having a child with special needs on couple functioning has been split. Regarding risk of divorce, a meta-analysis on marital adjustment in parents of children with various disabilities and found a small, but detectable, negative impact in parents of children with a disability, with an average of 5.97% more divorces (Risdal & Singer, 2004). Outside of divorce, relationship quality may also be affected by the presence of a child with special needs in the family. Parents of children with a developmental disability report more marital stress than is reported by parents of typically developing children (Marshak & Prezant, 2007). However, higher marital quality has been shown to be a protective factor against stress in parents of children with developmental disabilities (Kersh et al., 2006). Although literature has examined how having a child with special needs may affect relationship stress and stability, less

has been done specifically to investigate relationship quality of parents of a child with Down syndrome.

Relationship Quality

Several factors have been shown to be associated with relationship quality, including attachment style, personality traits, and levels of stress (Muslow, Caldera, Pursley, Reifman, & Huston, 2002; Noftle & Shaver, 2006). Few studies have specifically examined how relationship quality is impacted by the presence of a child with special needs in the family. Some literature has focused on how role strain and role sharing may affect marital satisfaction in this population. Greater role strain related to child-care tasks has been found to be related to both marital satisfaction and depression in both mothers and fathers (Quittner et al., 1998). Partner stress in parents of children with Down syndrome has been shown to be significantly associated with both mothers' and fathers' stress (Roach, Orsmond, & Barratt, 1999), demonstrating partner effects in this population. This finding may call for more understanding of how partners' stress in parents of children with Down syndrome may affect relationship quality. In families in which mothers are the primary caregivers of the child with special needs, mothers may be especially affected by these challenges.

Measuring relationship quality may be more complex than perceptions of relationship satisfaction alone. Spanier and Cole (1976) discussed multiple dimensions of the couple relationship as contributing to relationship quality, including consensus on matters of importance to marital functioning, dyadic satisfaction, and dyadic cohesion. In parents of children with a developmental disability, Bristol (1988) found that role strain specifically was associated with lower reports of relationship adjustment. Capelli (1990) also found that parents of a child with special needs reported less intimacy and more stress and role strain. Relationship quality has

been linked to parent well-being (Kersh et al., 2006); however, less is known about what factors may contribute to relationship quality in parents of children with Down syndrome.

Coping

The presence of coping behaviors in parents of children with Down syndrome are helpful to consider in the face of the unique challenges and experiences that often are present when raising a child with special needs. Previous studies have found that parents of children with special needs may exhibit both positive and negative coping strategies, such as problem solving, accepting responsibility, positive reappraisal of events, or escape/avoidance (Glidden, Billings, & Jobe, 2006). In a study by Sivberg (2002), parents of children with autism were found to have higher levels of stress and different coping strategies, such as distancing and escape behaviors, than parents with a child without autism. Parents of children with autism also reported more avoidant coping behaviors (Sivberg, 2002).

Some gender differences may exist in regards to the sex of the parent. For example, Sullivan (2002) found that mothers of a child with Down syndrome scored higher than fathers in planning, seeking social support, seeking religious support, and venting emotions on a measure of coping strategies. Although differences were found, mothers and fathers were both shown to be actively coping, showing engagement and using coping strategies (Sullivan, 2002). Although many studies have examined coping strategies in parents of children with special needs, fewer studies are specific to parents of children with Down syndrome. A study by Nelson Goff, Monk, Malone, Staats, Tanner, and Springer (in process) found that differences may exist in regards to age of the child with Down syndrome, in which parents of children in middle childhood (ages 5-11) were shown to have higher coping strategy scores than parents whose child with Down syndrome was younger or older. Additionally, parents of children with Down syndrome have

described the importance of accepting their child's diagnosis, having a positive attitude, and utilizing spiritual support as forms of coping with the Down syndrome diagnosis (Nelson Goff et al., in process).

Examining coping methods in parents of children with special needs may highlight the resilience present in this population. In one study, couples coping together by being sensitive to one another's stress signals was shown to be significantly associated with marital quality over a period of two years (Bodenmann, Pihet, & Kayser, 2006). Cognitive coping in parents of children with Down syndrome have also been shown to decrease parental stress (Atkinson et al., 1995; Shelly, van der Veek, Kraaij, & Garnefski, 2009). More information is needed in order to understand the effects coping behaviors may have on relationship quality in parents of children with Down syndrome.

Hope

According to Snyder (2002), hope is "a positive motivational state that is based on an interactively derived sense of successful agency and pathways" (p. 250) and has been associated with adaptive coping as well as lower levels of depression and anxiety. Additionally, Snyder (2002) describes individuals with high levels of hope as "very good at producing plausible alternate routes" and as "flexible thinkers" (p. 251). This flexibility described in hopeful persons may be helpful for parents of children with a developmental disability. For parents of children with Down syndrome, receiving their child's initial diagnosis is often a stressful experience in which alterations must be made to expectations of a typically developing child. Drawing on hope as described by Snyder above, parents of children with Down syndrome may be able to use their flexibility in thinking as a resource for their adjustment.

In one qualitative study, parents of children with Down syndrome shared the importance of hope and seeing the possibilities for the future (King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006). Having a positive attitude about the future has also been emphasized by parents of children with Down syndrome in dealing with challenges that may arise in parenting (Nelson Goff et al., in process). In relationship to parenting, hope has been associated with caregiver adaptation to stress in parents of children with Down syndrome (Truitt, Biesecker, Capone, Bailey, & Erby, 2012). Studies of mothers of children with Down syndrome have shown that higher levels of hope was associated with lower levels of worry, and is a contributing factor to psychological well-being (Lloyd & Hastings, 2009; Ogston, Mackintosh, & Myers, 2011). Hope in parents of children with special needs has also been associated with subjective well-being, or happiness (Shenaar-Golan, 2015). Although hope has been shown to be an important factor for individual functioning, the connection between hope and relationship quality has not been specifically assessed in mothers of children with Down syndrome. As hope has been seen as a significant factor in functioning of parents with a child with special needs, more knowledge is needed in regards to how this may contribute to parent relationship outcomes.

The Present Study

Literature regarding parents of children with Down syndrome has reviewed the importance of coping and hope to improve levels of functioning, however these studies have largely been focused on individual well-being or on the parent-child relationship. While coping and hope have been shown to be important factors in the lives of these parents, less is known about how these variables may have an effect on the subsystem of the parent relationship within the larger family system. The present study uses the intimate partnership between parents of children with Down syndrome as the focus of analysis in order to examine the association

between coping behaviors and relationship quality. In this study, relationship quality was measured by two established constructs of marital satisfaction and dyadic adjustment. It is hypothesized that hope will mediate the relationship between internal coping, religious coping, and support seeking coping and relationship quality.

Chapter 3 - Method

Procedure

Participants in this study were recruited as a part of a larger study through several local and national Down syndrome groups, including the National Down Syndrome Congress (ndsccenter.org; research webpage and national newsletter), Down Syndrome Guild of Greater Kansas City (kcdsg.org; webpage and newsletter), Band of Angels (bandofangels.com), and the Council for Exceptional Children (cec.sped.org). In order to facilitate recruiting, the NDSC forwarded information to points of contact at each of the affiliate organizations nationwide, which then distributed the study information through their local membership listservs. The research procedure was approved by the Kansas State University and Texas Tech University Institutional Review Boards (IRBs). Recruitment materials provided information about the study as well as the survey link to allow interested participants to access and complete the survey online. The web-based survey included both quantitative scale measures and qualitative questions for participants. Participants from 38 states and one other country completed the online survey.

Participants

For the present analysis, the inclusion criterion for the current study was that all participants must be in a romantic relationship and have a child with Down syndrome. Of the 644 total survey responders, only the cases that represented individuals who were either married, engaged, dating, remarried, or living together were selected. Because some of the participants were paired couples, to reduce the potential bias caused by paired data, and because of the lower numbers of males who participated in the study, only female participants were included in the current analysis. This reduced the participants for the present study to a final sample size of $N =$

351. Of the participants, most were European American/White (99.5%; *n* = 349), and in their first marriage (*n* = 320; 78%). This sample was of relatively high socioeconomic status, as 65.8% (*n* = 231) of participants reported having an annual family income at or above $70,000, with a large number who were employed full-time (39.6%; *n* = 139). This sample also represented a wide range of ages, between 16 and 70 years, with a mean age of 41.66 (*SD* = 9.32). See Table 3.1 for additional descriptive statistics describing the participants in this sample.

Table 3.1

Participant Demographic Statistics (N = 351 mothers)

Variables	n	%
Race		
European American / White	317	90.3
Latino/Hispanic	15	4.3
African American	2	0.6
American Indian or Alaska Native	3	0.9
Asian or Pacific Islander	2	0.6
Other	10	2.8
Employment		
Full-time	139	39.6
Part-time	76	21.7
Unemployed (no disability)	19	5.4
Unemployed (disability)	4	1.1
Retired	11	3.1
Full-time student	9	2.6
Part-time student	8	2.3
Full-time homemaker	102	29.1
Religion		
Protestant	147	41.9
Catholic	86	24.5
Jewish	15	4.3
Non-denominational	55	15.7
None	33	9.4
Other	11	3.1

Age		
16 - 25	9	2.6
26 - 30	32	9.2
31 - 40	134	38.1
41 - 50	118	33.5
51 - 60	46	13.2
61 - 70	12	3.5
Relationship length		
1 - 5 years	43	12.3
6 - 10 years	89	25.4
11 - 20 years	142	40.5
21 - 30 years	76	21.7
31 - 40 years	11	3.1
41+ years	7	2
Number of children		
1	54	15.4
2	101	28.8
3	115	32.8
4	43	12.3
5	15	4.3
6 or more	21	6.1
Number of marriages	1.23	1.07
0	9	2.6
1	278	79.2
2	51	14.5
3 or more	10	2.9
Income		
Below 9,999	5	1.4
10,000 - 19,999	10	2.8
20,000 - 29,999	12	3.4
30,000 - 39,999	11	3.1
40,000 - 49,999	25	7.1
50,000 - 59,999	25	7.1
60,000 - 69,999	23	6.6
70,000 - 79,999	23	6.6
80,000 - 89,999	37	10.5
90,000 - 99,999	35	10
100,000 and above	136	38.7

Measures

Coping behaviors. The Family Crisis Oriented Personal Evaluation Scales (F-COPES; McCubbin, Olson, & Larsen, 1991) is a 30-item, five-subscale measure used to quantify coping strategies employed by families facing challenging situations. Respondents are asked to rate their use of each coping strategy on a scale from 1 *(strongly disagree)* to 5 *(strongly agree)*; for the current study, participants were asked to retrospectively rate their coping strategies at the time of their child's Down syndrome diagnosis.

For the current study, various items from F-COPES were combined into three different types of coping: religious coping, internal coping, and seeking external support. Exploratory factor analyses indicated that each of these scales were representative of a single factor. Four items were used to assess a parent's level of *religious coping*, including attending church services, participating in church activities, seeking advice from a minister or other spiritual leader, and having faith in God. Higher scores on this subscale indicated higher use of religious coping behaviors. Cronbach's alpha reliability for religious coping was .87. Six items were used to create a subscale for *support seeking coping*. These items asked participants to rate themselves in terms of actively sharing their concerns by sharing difficulties and concerns with friends and relatives, as well as seeking assistance from neighbors and community agencies. Higher scores on this subscale indicated higher use of seeking emotional support behaviors. Cronbach's alpha reliability for this subscale was .73. Six items were used to assess a parent's level of *internal coping*. These questions focused on assessing participants' own perceptions of coping methods, such as feeling confident in their abilities to problem solve and seek solutions as well as appraisal of events in a way that is more helpful, such as accepting stresses as normal and defining the problem in a more positive way. Higher scores on this measure indicate higher use

of internal coping behaviors. Cronbach's alpha reliability for this subscale was .82. Each of these coping measures was computed by taking the means of each subscale's items.

Hope. The Herth Hope Index (HHI; Herth, 1992) is a 12-item scale adapted from the Herth Hope Scale (HHS). The measure is meant to be a scale used to assess hope in adults in clinical settings (Herth, 1992). Respondents are asked to rate how much they agree with statements such as, "I believe that each day has potential" and "I can see possibilities in the midst of difficulties." Items are scored on a 4-point Likert scale from 1 *(strongly disagree)* to 4 *(strongly agree)*; scores range from 12 to 48, with higher scores indicating higher levels of hope. The measure of hope was created by computing the means of each of the 12 items. This scale has been shown to be both a reliable and valid measure (Herth, 1992). Cronbach's alpha for the current study was .86, showing good internal consistency**.**

Relationship quality. A latent variable with two indicators was created to assess relationship quality. Both indicators represented well-established measures of relationship quality: the Revised Dyadic Adjustment Scale (Busby, Christensen, Crane, & Larson, 1995) and the Couples Satisfaction Index (Funk & Rogge, 2007). These measures are hereafter described**.**

The Revised Dyadic Adjustment Scale (RDAS; Busby et al., 1995) is a 14-item, three subscale measure used to assess relationship adjustment. Items are scored on variable Likert scales. Scores range from 0 to 69, with higher scores indicating higher relationship adjustment. Some sample items of this scale include "How often do you and your partner work together on a project?" and "How often do you and your partner quarrel?" Cronbach's alpha for the full sample in the current study was .87.

The Couples Satisfaction Index (CSI; Funk & Rogge, 2007) is a scale that measures relationship satisfaction; for this study, the 4-item version was used. Scores on this shortened

version of the CSI range from 0 to 21, with higher scores indicating higher relationship satisfaction. Respondents were asked to rate their relationship using questions such as "I have a warm and comfortable relationship with my partner" and "How rewarding is your relationship with your partner?" This scale has been shown to be both a reliable and valid measure of relationship satisfaction (Funk & Rogge, 2007). Cronbach's alpha for the full sample in the current study was .94, showing a high level of internal consistency.

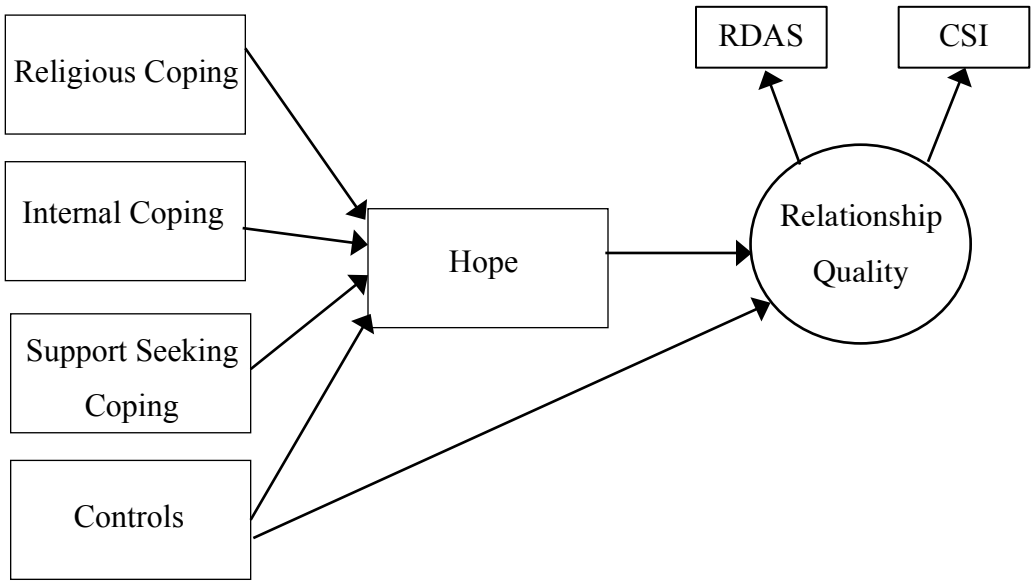
Control variables. Various control variables were included in this study. As the sample for the present analysis was limited to mothers, gender was not used as a control measure. Due to the sample being primarily White, race was coded as a binary control variable (1 = *white*; 0 = *nonwhite*) as cell sizes for minority groups were not large enough to consider statistically viable to compare. To measure employment, participants were asked to identify themselves in one of the following categories: employed full-time, employed part-time, unemployed not due to a disability, unemployed due to a disability, retired, full-time student, part-time student, and full-time homemaker. For the present study, employment was coded as a binary variable (1= *employed;* 0 = *unemployed*). Religion was also coded as a binary variable. Participants who described themselves as having any religious preference (Protestant, Catholic, Jewish, Muslim, Non-denominational) were coded as religious, while those who chose "None" were considered nonreligious. Continuous control variables included age of mother, relationship length (measured in years), total number of children, and number of marriages. Finally, income was treated as continuous as eleven categories in the survey were given as choices for response, separated by intervals of $10,000 up to $100,000 or more.

Analysis Plan

Data were prepared using IBM SPSS Statistics, Version 22. All variables and measures were tested to meet the assumptions of normality before analyzing the predicted model. A structural equation model was created guided by theory and previous literature. The three subscales of the F-COPES were assessed with an exploratory factor analysis and it was confirmed that each of the three coping subscales represented a single factor. The latent variable "Relationship Quality" was specified as having two indicators, the Couple Satisfaction Index (CSI) and the Revised Dyadic Adjustment Scale (RDAS). Confirmatory factor analyses for this latent variable is not available, as only two indicators are used; however, both indicators have shown in the past to be both reliable and valid measures of relationship outcomes. Once assumptions of normality were met, data were analyzed using MPLUS, Version 7.3 (Muthén & Muthén, 2015) to test the predicted model. The default method to handle missing data in this system is the use of full information maximum likelihood. As a part of the analysis, bootstrapping procedures were used to test the significance of indirect effects, and the indirect effects were tested with 95% confidence intervals. Figure 3.1 presents the conceptual model, with hope as a mediator for the association between coping behaviors and relationship quality. This proposed model included hope as a mediator for the relationship between religious coping, internal coping, and relationship quality, while controlling for race, age, relationship length, number of marriages, employment, income, religiosity, and total number of children.

Figure 3.1.

Conceptual SEM Model



Chapter 4 - Results

Assumptions and Correlations

Before computing the hypothesized model, statistical assumptions were evaluated using SPSS (Version 22). All individual variables in the model were identified as acceptable according to recommendations by Kline (2011). Additionally, all variables used in the model met the assumptions of multivariate normality and linearity. Correlations between all variables were calculated. First, hope was found to be significantly correlated with all three coping subscales: religious coping ($r = .338$, $p < .001$); internal coping ($r = .368$, $p < .001$); and seeking support coping ($r = .197$, $p <001$). Hope was also significantly correlated with dyadic adjustment ($r = .312$, $p < .001$) as well as with relationship satisfaction ($r = .386$, $p < .001$). For all other zero-order correlations, see Table 4.1.

Structural Equation Model

Before interpreting parameter estimates, model fit was assessed. The proposed model demonstrated good model fit across multiple model fit statistics. The chi-square was nonsignificant (χ^2 (11) = 18.51, $p = .07$), indicating good model fit to the data. Other model fit statistics such as Comparative Fit Indices (CFI) = .98, Root Mean Square Error of Approximation (RMSEA) = .04 (90% CI = .001, .08), and Standardized Root Mean Square Residual (SRMR) = .01 also showed acceptable model fit results.

Direct Effects

Direct effects linking coping behaviors to hope were found in the model. Religious coping was significantly associated with hope ($b = .09$, $p < .001$, $\beta = .29$). Internal coping was also found to be significantly associated with hope ($b = .14$, $p < .001$, $\beta = .29$). The third type of coping measuring support-seeking behaviors was not shown to be significantly associated with

hope. No control variables in the model were seen to be associated with hope. A direct effect was also shown in the model to associate hope with relationship quality ($b = 1.099$, $p < .001$, $\beta = .44$) No control variables were shown to be significant direct effects associated with relationship quality. This model accounted for 21% of the variance in relationship quality and 23% of the variance in hope. No direct effects between coping behaviors and relationship quality were found. All other parameter estimates are shown in Table 4.2.

Indirect Effects

Two significant indirect effects were found in the present analysis. Bootstrapping procedures produced a 95% confident interval (CI) for each indirect effect in order to test significance. As per recommendations by Kline (2011), if 0 was not found within the computed 95% confidence interval, mediation effects were considered significant. The relationship between religious coping behaviors and relationship quality was significant when mediated by hope ($b = .10$, $p < .001$, $\beta = .13$, CI = .06, .16). Additionally, internal coping was also indirectly associated with relationship quality through hope ($b = .16$, $p < .001$, $\beta = .13$, CI = .08, .26). These results can be interpreted to mean that both religious coping and internal coping behaviors are significantly and positively related to relationship quality via hope. As religious and internal coping behaviors increase, relationship quality also increases by an indirect effect. Significant indirect results are shown in Table 4.3.

Figure 4.1

Coping Behaviors Associated with Relationships Quality via Hope (N = 351 Mothers). Standardized Results shown.

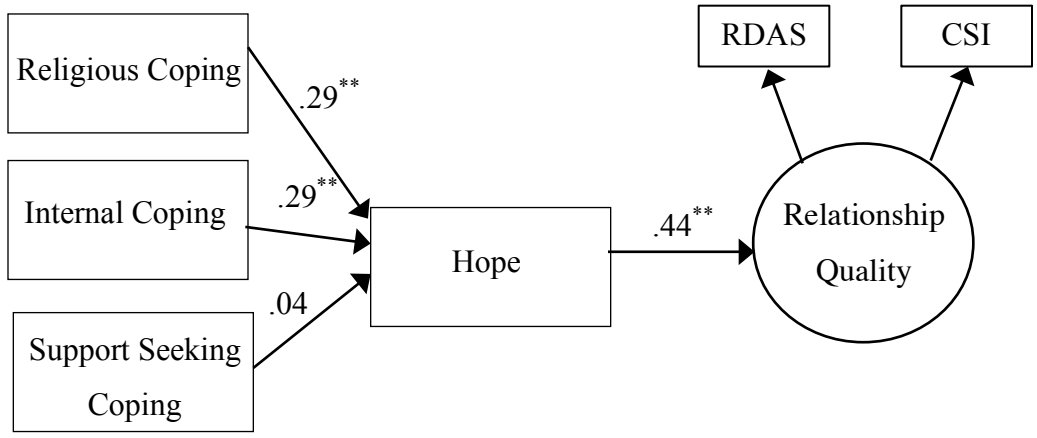


Table 4.1

Correlations and Descriptive Statistics (N = 351 mothers)

Variables	1	2	3	4	5	6	7	8	9
1.Religious coping	1								
2. Internal coping	.18**	1							
3. Seeking support coping	.29**	.28**	1						
4. Hope	.34**	.37**	.20**	1					
5. Dyadic adjustment	.09	.05	.03	.31**	1				
6. Relationship satisfaction	.12*	.12*	.05	.39**	.69**	1			
7. White	.08	-.07	.03	.02	.10	-.02	1		
8. Employed	-.05	.08	-.00	.05	-.06	-.02	-.06	1	
9. Religious	.48**	-.05	.04	.09	.02	-.03	.08	-.06	1
10. Age of mother	.14**	-.02	-.04	.04	.02	-.03	.06	.04	.17**
11. Relationship length	.12*	-.10	.01	-.04	.03	-.02	.03	-.03	.13*
12. Number of children	.08	.03	-.04	.12*	.08	.02	-.06	-.11*	.01
13. Number of marriages	.03	-.07	-.09	.06	-.08	-.05	.05	.07	.09
14. Income	.01	.13*	.02	.08	.08	.11*	.01	.17**	.02
M	3.07	3.80	3.38	3.52	3.47	3.46	.91	.63	.90
SD	1.27	.81	.81	.40	.65	1.07	.29	.48	.30
Range	1 - 5	1 - 5	1 - 5	0 - 5	1 - 5	1.5 - 4	0 - 1	0 - 1	0 - 1
α	.87	.82	.73	.86	.87	.94			

Table 4.1

Continued

Variables	10	11	12	13	14
10. Age of mother	1				
11. Relationship length	.74**	1			
12. Number of children	.29**	.33**	1		
13. Number of marriages	.15**	-.02	-.01	1	
14. Income	.18**	.07	-.04	-.06	1
M	41.43	14.90	2.91	1.23	8.49
SD	9.39	9.06	1.87	1.07	2.84
Range	16 - 70	1 - 51	1 - 22	0 - 18	1 - 11
α					

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

Table 4.2

Direct Effects on Hope and Relationship Quality (N = 351 Mothers)

	Hope			Relationship Quality		
Variable	*b*	*SE b*	*β*	*b*	*SE b*	*β*
Religious coping	.09**	.02	.29	.04	.05	.06
Internal coping	.14**	0.03	.29	-.07	0.08	-.06
Seeking support coping	.02	.03	.04	-.05	0.08	.04
Hope	-	-	-	1.10**	.19	.44
White	.03	.08	.02	-.01	.25	-.00
Employment	.02	.04	.03	-.12	.12	-.06
Religious	-.05	.07	-.04	-.33	.22	-.10
Age of mother	.00	.00	-.01	-.01	.01.	-.08
Relationship length	-.00	.00	-.06	.01	.01	.06
Number of children	.02	.02	.11	-.01	.03	-.02
Number of marriages	.03	.03	.08	-.05	.10	-.05
Income	.01	.01	.04	.04	.02	0.11
R^2		.23			.21	

**$p < .01$.

Table 4.3

Mediating Effects for Internal Coping and Religious Coping as Independent Variables, Hope as Mediator, and Relationship Quality as Outcome Variable. Bootstrap Analyses of the Magnitude and Significance of Mediating Pathways (Standardized Solution; N = 351 Mothers)

Predictor	Mediator(s)	Outcome	β	CI	*t*-value
Religious coping→	Hope→	Relationship Quality	.13	.05, .20	3.55**
Internal coping→	Hope→	Relationship Quality	.13	.05, .20	3.40**

Note: ***p* < .001 (two-tailed). Indirect paths tested with 2,000 bootstraps. CI = 95% confidence interval.

Chapter 5 - Discussion

The current study included a sample of 351 mothers from a larger national sample of parents of children with Down syndrome who completed measures on coping, hope, relationship satisfaction and dyadic adjustment. The purpose of the current study was to examine the relationship between coping behaviors and relationship quality, with hope acting as a mediator. The present analysis tested a model showing hope mediated the association between religious coping, internal coping, support seeking coping, with relationship quality. Previously, researchers have not addressed specifically which factors may lead to better intimate partner relationship outcomes in parents of children with Down syndrome. The current results indicated that both religious coping and internal coping were significantly associated with higher levels of relationship quality, as mediated by hope. Support seeking coping was not found to have a significant direct or indirect effect on relationship quality. The results of this study provide additional support for previously published literature regarding this population, as well as yield various implications for parents of children with Down syndrome, family professionals, and communities.

This study provides additional support for previous findings in the literature as well as presents some contrasting results that imply future research is needed. Although previous studies have shown that coping behaviors have a direct effect on relationship quality (Bodenmann et al., 2006), the current study found only indirect links between religious coping, internal coping, and relationship quality. While these results are contrasting, several considerations must be made before interpretation can occur. Further research should be conducted in order to determine the effect of mediating variables such as hope in parents of typically developing children. This may shed light on whether this effect is specific to this population.

According to Stoneman and Gavidia-Payne (2006), higher marital adjustment in parents of children with disabilities was associated with problem-focused coping, in which practical measures are taken to reduce the effects of the stressor. Findings of the current study provide some support for the Stoneman and Gavidia-Payne (2006) finding, as both religious coping and internal coping strategies were related to higher levels of dyadic adjustment when mediated by hope. The current study, however, implies that coping in itself is not enough to affect change in a couple's relationship, and that hope is an important aspect of this equation.

Sullivan (2002) found that mothers of children with Down syndrome were more likely to turn to religion in order to cope with parenting related stress as compared to fathers. The present study provides support for the use of religious coping by mothers of children with Down syndrome and extends the literature by making it relevant to change in the intimate partnership between parents. Internal coping behaviors were also found to be linked with relationship quality through hope. According to Shelley, van der Veek, Kraaij, and Garnefski (2009), positive reappraisal was associated with lower levels of parenting stress in parents of children with Down syndrome. This study provides support for this finding as a similar result was found regarding the indirect link between internal coping behaviors and relationship quality. Again, this study expands past findings by providing a focus on the intimate partnership rather than previous findings that focused on outcomes of parental stress (Cappelli, 1990; Kersh et al., 2006). Finally, the indirect relationship between coping and relationship quality when mediated by hope supports previous qualitative findings in which parents of children with Down syndrome described both the importance of maintaining a positive attitude as well as their use of coping strategies related to seeking spiritual support and drawing on inner personal strengths (Nelson Goff et al., in process).

Revisiting Boss' (2002) contextual model of family stress, the results of this study add to literature regarding which resources may make a difference in this population. According to the contextual model, increasing resources in a system to effectively face challenges can help decrease stress and prevent crisis (Boss, 2002). Many previous studies examine stress in parents of children with special needs and even uniquely parents of children with Down syndrome; however, the intimate partnership that exists between the parents of these children is less often the focus.

Resources can also be seen as a way to strengthen subsystems of the family in order to spur positive changes in the overall family system. Hope has been shown to increase parental adaptation to stress in families with a child with Down syndrome (Truitt et al., 2012). Additionally, parents of children with Down syndrome emphasized the role of hope in their lives (King et al., 2006). The results of the present study seem to expand the benefits of fostering hope in parents of children with Down syndrome from beyond decreasing parental stress to affecting positive outcomes in the intimate partnership of the parents. In this way, the resource of hope can be seen as having multifaceted benefits. Framing hope as a resource may be helpful for family professionals as they work with parents of children with Down syndrome.

In the present analysis, religious coping was shown to have an indirect effect on relationship quality when mediated by hope. In one study, levels of spiritual meaning-making was significantly related to increased amounts of hope (Ciarrocchi, Dy-Liacco, & Deneke, 2006). The present analysis adds to this finding by addressing the more specific population of mothers of children with Down syndrome and examining how religious coping and hope can lead to higher relationship quality. This study conceptualized religious participation and having faith in God as a coping strategy for parents, which may assist in meaning-making and affect levels of

hope, having an indirect effect on relationship quality. Implications for parents of children with Down syndrome may include considering connecting with a faith community in order to gain hope and to indirectly improve their intimate partnership. For professionals working with a couple struggling with the Down syndrome diagnosis may therefore wish to explore the family's belief systems and how religious and or spiritual practices may serve as coping strategies to improve relationship functioning. On the community level, religious and spiritual organizations may wish to consider their own role in supporting parents of children with special needs in order to be sensitive to the needs of these families. This fits with the recommendations of King et al. (2006) in that identifying and responding to the beliefs and values that are important to families of children with Down syndrome is a crucial step of the helping relationship between families and service providers.

In addition to religious coping, internal coping also was shown to have an indirect effect on relationship quality when mediated by hope. In this study, behaviors such as believing in one's own power to solve problems, drawing on family strengths to face difficulties in life, and redefining family problems in positive ways were considered internal coping efforts. Previous literature has examined cognitive coping efforts in parents of children with Down syndrome and found positive reappraisal to be associated with higher subjective well-being (King, Scollon, Ramsey, & Williams, 2000), as well as lower levels of parenting stress (Shelley et al., 2009). Acceptance has also been associated with lower levels of parenting stress in other studies (Nelson Goff et al., in process; Shelley et al., 2009). The present study found internal coping was positively and directly linked to hope and indirectly to relationship quality. In order to promote higher levels of relationship quality, the current results imply that parents of children with Down syndrome may seek to hone their own internal resources as a way to improve their marital/couple

relationship. Providing support and encouragement between spouses may be a way to foster internal resources in parents of children with Down syndrome as a mechanism of improving their relationship quality.

Implications for Professionals

Parents facing a Down syndrome diagnosis in their child experience a myriad of decisions and uncertainty, which may contribute to levels of stress. The diagnosis can bring some feelings of grief and loss for parents, but parents often describe the positives gained from their experiences parenting a child with Down syndrome (Nelson Goff et al., in process). Couples raising a child with Down syndrome may seek services either for issues related to adjusting to the diagnosis, parenting stress, or for other concerns. Professionals should be contextually sensitive when working with these couples and consider the challenges these parents may face. From a systemically geared perspective, these results have implications for professionals working with parents with a child with Down syndrome. Challenges associated with raising a child with Down syndrome have been linked not only to individual parent stress, but also with partner stress (Roach et al., 1999) implying an effect on the intimate partnership. It is important that resources be identified for families with a child with Down syndrome in order to guide professional recommendations for practice in order to remediate stress and the side effects this stress may cause within the family, such as relationship strain. Additionally, these results may suggest that instilling hope and encouraging internal and/or religious or spiritual coping may be helpful in order to progress toward better relationship functioning for couples. From a structural perspective, strengthening the parental subsystem in terms of the couple relationship has the power to enact change in other subsystems within the family, such as parent-child interactions and sibling relationships.

Professionals working with more diverse populations, should interpret results of the present analysis carefully, and take into consideration the needs that those of different racial backgrounds and socioeconomic status may have. Respectful and culturally competent services should take into account the contextual placement of parents of children with Down syndrome.

Study Limitations and Future Research

The current study adds to the literature on hope, coping, and relationship quality for mothers of children with Down syndrome, while expanding the field by researching the intimate partnership, which is a less examined focus of attention. The present analysis also included a quantitative method to investigate the relationship between mothers of children with Down syndrome, whereas past studies have tended to use more qualitative approaches, with smaller samples, or that involved less complex quantitative methodology. Although the sample was a nationally recruited group, there are various limitations of this study that imply further research is needed. First, the participants in this sample were predominantly White and all were female, who reported higher socioeconomic status, as over half of participants reporting having a family income of $70,000 or above. Future research should examine how factors that contribute to relationship quality may vary among persons of various racial, ethnic and from broader socioeconomic backgrounds. In addition, male respondents' observations were not included in the current analysis, due to existing paired couples data, in order to avoid potential bias in the study results. Future studies should consider using dyadic data in order to gain a more complete view of the intimate relationship functioning in couples. Because of the limited sample size of male participants, the current study was not able to analyze the data using dyadic data analysis methods due to nonindependence of the data and potential bias in the data analysis (Cook & Snyder, 2005). Future research that includes perspectives from both partners would be beneficial,

as this is a limitation in the broader field as well as the current study. Also, while the current study was a nationally-recruited sample, with several efforts made to recruit more diverse participant groups, future dyadic studies may also wish to examine couples who are diverse regarding sexual orientation and partnership, especially taking into account both lesbian and gay couples who are parenting a child with Down syndrome and other special needs.

As researchers continue to study the effects of having a child with Down syndrome on individuals and families, it is important that the intimate partnership not be left out of consideration. Understanding how various coping behaviors and having hope can affect the relationship between parents of children with Down syndrome has the potential to inform both professionals working with families with a child with Down syndrome as well as individuals and families themselves looking for new strategies to improve their relationships and family functioning.

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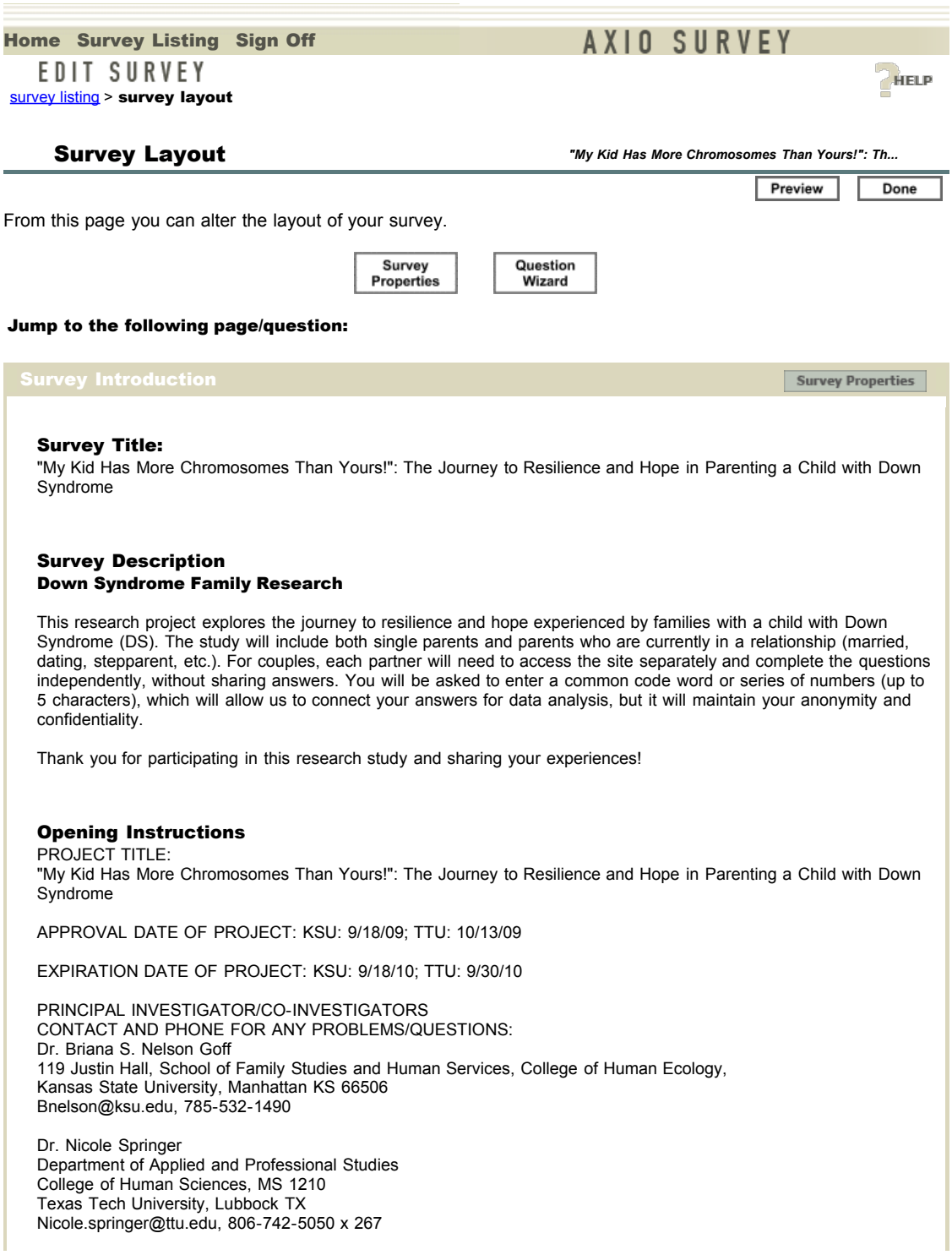
Appendix A - Web Survey

Axio Survey



Home Survey Listing Sign Off AXIO SURVEY

EDIT SURVEY

HELP

survey listing > **survey layout**

Survey Layout *"My Kid Has More Chromosomes Than Yours!": Th...*

Preview Done

From this page you can alter the layout of your survey.

Survey Properties Question Wizard

Jump to the following page/question:

Survey Introduction Survey Properties

Survey Title:
"My Kid Has More Chromosomes Than Yours!": The Journey to Resilience and Hope in Parenting a Child with Down Syndrome

Survey Description
Down Syndrome Family Research

This research project explores the journey to resilience and hope experienced by families with a child with Down Syndrome (DS). The study will include both single parents and parents who are currently in a relationship (married, dating, stepparent, etc.). For couples, each partner will need to access the site separately and complete the questions independently, without sharing answers. You will be asked to enter a common code word or series of numbers (up to 5 characters), which will allow us to connect your answers for data analysis, but it will maintain your anonymity and confidentiality.

Thank you for participating in this research study and sharing your experiences!

Opening Instructions
PROJECT TITLE:
"My Kid Has More Chromosomes Than Yours!": The Journey to Resilience and Hope in Parenting a Child with Down Syndrome

APPROVAL DATE OF PROJECT: KSU: 9/18/09; TTU: 10/13/09

EXPIRATION DATE OF PROJECT: KSU: 9/18/10; TTU: 9/30/10

PRINCIPAL INVESTIGATOR/CO-INVESTIGATORS
CONTACT AND PHONE FOR ANY PROBLEMS/QUESTIONS:
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Rosemary Cogan, Protection of Human Subjects Committee
203 Holden Hall, Texas Tech University, Lubbock TX 29409-1035

SPONSOR OF PROJECT:
N/A

PURPOSE OF THE RESEARCH:
This research will include online surveys and qualitative interviews with parents that will explore the journey to resilience and hope experienced by families with a child with Down Syndrome (DS). This research will identify the key resilience factors in families who have successfully navigated this difficult transition and provide important information and resources for families facing this journey in the future. Specific questions will ask participants how they coped with their child's Down syndrome diagnosis, about their relationship as a couple, and their hope and satisfaction with life. In addition, qualitative questions will ask more about their initial response to the diagnosis, their current attitude about the diagnosis, and other specific experiences they have had as a parent to a child with DS.

We anticipate two primary outcomes from this project: 1) academic publications and presentations based on the research data, and 2) a consumer media publication for families with children with DS. The consumer media publication for new parents of children with DS will include the experiences of parents, in their own words, as well as several key resources to help parents in this journey.

PROCEDURES OR METHODS TO BE USED:
The research will be conducted through an online survey questionnaire and will require approximately 45 minutes of your time.

If selected for a follow-up interview, phone interviews will be conducted that will require approximately 60-90 minutes of your time. Interview participants will receive a small incentive for their participation.

ALTERNATIVE PROCEDURES OR TREATMENTS, IF ANY, THAT MIGHT BE ADVANTAGEOUS TO SUBJECT:
N/A

LENGTH OF STUDY: 45 minutes for online survey; 60-90 minutes for interviews (selected participants)

RISKS ANTICIPATED:
Potential risks include:
1) an increased awareness of interpersonal issues within the participants' relationships and parenting,
2) an increased awareness of possible need for more professional assistance,
3) increased psychological distress from discussion of what may be a difficult life experience for some participants.

BENEFITS ANTICIPATED:
1) increased awareness of the personal impact and benefits of parenting a child with DS;
2) participation in the development of a mainstream publication for new parents of children with DS;
3) increased awareness of the strengths and positive aspects of parenting a child with DS.

EXTENT OF CONFIDENTIALITY:
Online survey participants who choose NOT to be potential interview participants will be anonymous. Participants who indicate they are willing to participate in follow-up interviews will be asked for their contact information at the end of the online survey. Not all participants who volunteer will be selected for the interviews. Interview participants will not be anonymous, because participants will be selected based on specific characteristics that will provide a diverse sample of parents for interviews (e.g., a variety of participants will be selected for the interviews based on varied ages, socioeconomic status, relationship status, geographic location, age of the child with Down Syndrome, etc.).

All printed records and audiotapes or digital recordings will be kept in locked cabinets or secure computers with access only by the researchers and their assistants. Once participants have been selected for their participation in the interviews, all identifying information will be omitted from the online data and interview transcripts. In the publications that result from this study (peer-reviewed academic publications and/or consumer media publications), all participant names and any other identifying information will be omitted and replaced by pseudonyms to maintain confidentiality.

IS COMPENSATION OR MEDICAL TREATMENT AVAILABLE IF INJURY OCCURS: No

PARENTAL APPROVAL FOR MINORS: N/A

TERMS OF PARTICIPATION: I understand this project is research, and that my participation is completely voluntary. I also understand that if I decide to participate in this study, I may withdraw my consent at any time, and stop participating at any time without explanation, penalty, or loss of benefits, or academic standing to which I may otherwise be entitled.

I verify that clicking "next" below indicates that I have read and understand this consent form and willingly agree to participate in this study under the terms described.

top of survey

Page 1: Family Coping Scale Delete Edit

Family Coping Scale

Page Instructions:

The following scale is designed to record effective problem-solving attitudes and behaviors that families develop to respond to problems or difficulties.

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 your child's diagnosis with Down syndrome. If the statement describes your response VERY WELL, then check 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 of disagree with the statement about your response.

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

Item #1 - Question

move to # Edit Copy Delete

When our family learned about our child's diagnosis with Down syndrome, we responded by:

1 - Strongly disagree | 2 - Moderately disagree
3 - Neither agree nor disagree | 4 - Moderately agree | 5 - Strongly agree

	1	2	3	4	5
1.1 sharing our difficulties with relatives					
1.2 seeking encouragement and support from friends					
1.3 knowing we have the power to solve major problems					
1.4 seeking information and advice from persons in other families who have faced the same or similar problems					
1.5 seeking advice from relatives (grandparents, etc.)					

1.6 seeking assistance from community agencies and programs designed to help families in our situation	○	○	○	○	○
1.7 knowing that we have the strength within our own family to solve our problems	○	○	○	○	○
1.8 receiving gifts and favors from neighbors (e.g., food, taking in the mail, etc.)	○	○	○	○	○
1.9 seeking information and advice from the family doctor	○	○	○	○	○
1.10 asking neighbors for favors and assistance	○	○	○	○	○
1.11 facing the problems "head-on" and trying to get solutions right away	○	○	○	○	○
1.12 watching television	○	○	○	○	○
1.13 showing that we are strong	○	○	○	○	○
1.14 attending church services	○	○	○	○	○
1.15 accepting stressful events as a fact of life	○	○	○	○	○
1.16 sharing concerns with close friends	○	○	○	○	○
1.17 knowing luck plays a big part in how well we are able to solve family problems	○	○	○	○	○
1.18 exercising with friends to stay fit and reduce tension	○	○	○	○	○
1.19 accepting that difficulties occur unexpectedly	○	○	○	○	○
1.20 doing things with relatives (get-togethers, dinners, etc.)	○	○	○	○	○
1.21 seeking professional counseling and help for family difficulties	○	○	○	○	○
1.22 believing we can handle our own problems	○	○	○	○	○
1.23 participating in church activities	○	○	○	○	○
1.24 defining the family problem in a more positive way so that we do not become too discouraged	○	○	○	○	○
1.25 asking relatives how they feel about problems we face	○	○	○	○	○
1.26 feeling that no matter what we do to prepare, we will have difficulty handling problems	○	○	○	○	○
1.27 seeking advice from a minister or other spiritual leader	○	○	○	○	○
1.28 believing if we wait long enough, the problem will go away	○	○	○	○	○
1.29 sharing problems with neighbors	○	○	○	○	○
1.30 having faith in God	○	○	○	○	○

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

top of survey

Page 2: Relationship Satisfaction Delete Edit

Relationship Satisfaction

Page Instructions:

The following questions ask about your current relationship. If you are not currently in a committed relationship (for example, married, dating, engaged, living together), please skip this section and go to the next page of questions.

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

Item #2 - Question

move to # [ ] Edit Copy Delete

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

1 - Always Agree | 2 - Almost Always Agree
3 - Occasionally Disagree | 4 - Frequently Disagree | 5 - Almost Always Disagree
6 - Always Disagree

	1	2	3	4	5	6
2.1 religious matters	○	○	○	○	○	○
2.2 demonstration of affection	○	○	○	○	○	○
2.3 making major decisions	○	○	○	○	○	○
2.4 sex relations	○	○	○	○	○	○
2.5 conventionality (correct or proper behavior)	○	○	○	○	○	○
2.6 career decisions	○	○	○	○	○	○

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #3 - Question

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1 - All the time | 2 - Most of the time | 3 - More often than not
4 - Occasionally | 5 - Rarely | 6 - Never

	1	2	3	4	5	6
3.1 How often have you discussed or considered divorce, separation, or terminating your relationship?	○	○	○	○	○	○
3.2 How often do you and your partner quarrel?	○	○	○	○	○	○
3.3 Do you ever regret that you married/entered the relationship with your partner?	○	○	○	○	○	○

3.4 How often do you and your partner "get on each other's nerves"?	○	○	○	○	○	○

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #4 - Question

move to # [ ] Edit Copy Delete

1 - Every day | 2 - Almost every day | 3 - Occasionally
4 - Rarely | 5 - Never

	1	2	3	4	5
4.1 Do you and your partner engage in outside interests together?	○	○	○	○	○

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #5 - Question

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

1 - Never | 2 - Less than once a month | 3 - Once or twice a month
4 - Once or twice a week | 5 - Once a day | 6 - More often

	1	2	3	4	5	6
5.1 Have a stimulating exchange of ideas	○	○	○	○	○	○
5.2 Work together on a project	○	○	○	○	○	○
5.3 Calmly discuss something	○	○	○	○	○	○

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scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #6 - Question

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Please indicate the degree of happiness, all things considered of your relationship.

○ Extremely Unhappy
○ Fairly Unhappy
○

A Little Unhappy
- ○ Very Happy
- ○ Extremely Happy
- ○ Perfect

insert the following here:
scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #7 - Question

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I have a warm and comfortable relationship with my partner.
- ○ Not at all true
- ○ A little true
- ○ Somewhat true
- ○ Mostly true
- ○ Almost completely true
- ○ Completely true

insert the following here:
scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #8 - Question

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1 - Not at all | 2 - A little | 3 - Somewhat | 4 - Mostly
5 - Almost completely | 6 - Completely

	1	2	3	4	5	6
8.1 How rewarding is your relationship with your partner?	○	○	○	○	○	○
8.2 In general, how satisfied are you with your relationship?	○	○	○	○	○	○

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scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

top of survey

Page 3 Delete Edit

Page Instructions:

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scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

Item #9 - Question

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Herth Hope Index

Below are a number of statements. Read each statement and indicate how much you agree with that statement right now.

1 - Strongly disagree | 2 - Disagree | 3 - Agree
4 - Strongly agree

	1	2	3	4
9.1 I have a positive outlook toward life.	○	○	○	○
9.2 I have short and/or long range goals.	○	○	○	○
9.3 I feel all alone.	○	○	○	○
9.4 I can see possibilities in the midst of difficulties.	○	○	○	○
9.5 I have a faith that gives me comfort.	○	○	○	○
9.6 I feel scared about my future.	○	○	○	○
9.7 I can recall happy/joyful times.	○	○	○	○
9.8 I have a deep inner strength.	○	○	○	○
9.9 I am able to give and receive caring/love.	○	○	○	○
9.10 I have a sense of direction.	○	○	○	○
9.11 I believe that each day has potential.	○	○	○	○
9.12 I feel my life has value and worth.	○	○	○	○

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #10 - Question

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Satisfaction With Life Scale

Below are five statements with which you may agree or disagree. Using the scale below, indicate your agreement with each item. Please be open and honest in your responses.

1 - Strongly disagree | 2 - Disagree | 3 - Slightly disagree
4 - Neither agree nor disagree | 5 - Slightly agree | 6 - Agree | 7 - Strongly agree

	1	2	3	4	5	6	7
10.1 In most ways my life is close to my ideal.	○	○	○	○	○	○	○
10.2 The conditions of my life are excellent.	○	○	○	○	○	○	○
10.3 I am satisfied with my life.	○	○	○	○	○	○	○
10.4 So far I have gotten the important things I want in life.	○	○	○	○	○	○	○
10.5 If I could live my life over, I would change almost nothing.	○	○	○	○	○	○	○

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

top of survey

Page 4: Qualitative Questions Delete Edit

Qualitative Questions

Page Instructions:

Please provide the following additional information to help us better understand your experiences in parenting a child with Down syndrome.

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

Item #11 - Question

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Describe the experience when you first learned of your child's diagnosis with Down syndrome:

- What were your initial reactions/emotions/thoughts?
- What was the process in adjusting to your child's diagnosis?
- What was your experience with prenatal testing? Would you make the same decision again?

Characters Remaining:

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scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #12 - Question

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Describe how you responded to your child's diagnosis compared to your spouse/partner.

- What similarities or differences were there between how you and your spouse/partner responded to the initial diagnosis?
- What do you see as the causes of those similarities or differences in your responses?
- What differences are there currently in how you and your spouse/partner respond to your child?

Characters Remaining:

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scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

top of survey

Page 5 Delete Edit

Page Instructions:

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scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

Item #13 - Question

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Describe your current attitude about your child's diagnosis with Down syndrome. If it is helpful, describe your rating on a scale of 1 (poor) to 10 (excellent).

Characters Remaining:

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Item #14 - Question

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How have you been most impacted personally by your child's diagnosis with Down syndrome?

Characters Remaining:

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scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #15 - Question

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Describe a time when you have been an advocate for your child.

Characters Remaining:

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scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

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Page Instructions:

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scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

Item #16 - Question

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Describe your most positive experience in your journey with your child.

Characters Remaining:

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scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #17 - Question

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Describe your most negative or most difficult experience in your journey with your child.

Characters Remaining:

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scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

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Page 7 Delete Edit

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scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

Item #18 - Question

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What advice would you have for other families who are preparing for a child with Down syndrome?

Characters Remaining:

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #19 - Question

move to # Edit Copy Delete

Is there anything else you feel is important for us to know?

Characters Remaining:

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

top of survey

Page 8: Background Information Delete Edit

Background Information

Page Instructions:

Please answer the following background questions. PLEASE DO NOT SKIP THIS SECTION. This information is important for us to understand the characteristics of our participants. Thank you!

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

Item #20 - Question

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For participants currently in a committed couple relationship (for example, married, dating, engaged, living together), in order to pair your survey with your spouse/partner's for the purpose of data analysis only, we ask that both of you complete the following question using the same information. This is for research coding purposes only.

Please enter a common code word (not your name or other identifier) or series of numbers (up to 5 characters), which will allow us to connect your answers with your spouse/partner's answers for data analysis.

IF YOU ARE NOT CURRENTLY IN A COMMITTED RELATIONSHIP, PLEASE SKIP THIS QUESTION.

Characters Remaining:

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #21 - Question

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Your gender:

☐ Male

☐ Female

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #22 - Question

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Your age:

Characters Remaining:

insert the following here:
scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #23 - Question

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What is your racial/cultural/ethnic origin? (Please check one)
- ○ American Indian or Alaska Native
- ○ Asian or Pacific Islander
- ○ African American (Black), not of Hispanic origin
- ○ Latino/Hispanic
- ○ European American/White
- ○ Other:

insert the following here:
scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #24 - Question

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What is your current relationship status?
- ○ Married
- ○ Dating
- ○ Engaged
- ○ Currently separated
- ○ Divorced, not currently in another relationship
- ○ Remarried
- ○ Living Together
- ○ Other:

insert the following here:
scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #25 - Question

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How long have you been in your current relationship? (Please state in whole years; If less than 1 year, put "<1")

Characters Remaining:

insert the following here:
scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #26 - Question

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Total number of marriages (**INCLUDING** current marriage)

Characters Remaining:

insert the following here:
scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #27 - Question

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Total number of children (including step children and adopted children):

Characters Remaining:

insert the following here:
scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #28 - Question

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Total number of children with Down syndrome:

Characters Remaining:

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #29 - Question

move to # [ ] Edit Copy Delete

Current age of Child with Down syndrome (if more than one child has Down syndrome, list all ages, separated by commas):

Characters Remaining:

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #30 - Question

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Gender of Child with Down syndrome (if more than one child has Down syndrome, list the total number and gender of each child in the space below; e.g., Male children with DS= 2, female children with DS = 1):

☐ Male

☐ Female

Further comments about your response:

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #31 - Question

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How did you learn of your child's diagnosis?

○ After birth through a chromosome/blood test

○ Early ultrasound markers during pregnancy

○ Amniocentesis results during pregnancy

○ CVS biopsy during pregnancy

○ Other:

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #32 - Question

move to # [ ] Edit Copy Delete

What is the highest level of education that you have completed?

- ○ No formal education
- ○ Some grade school
- ○ Completed grade school
- ○ Some high school
- ○ Completed high school
- ○ Some college
- ○ Completed college
- ○ Some graduate work
- ○ Completed master's degree
- ○ Completed doctorate

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #33 - Question

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What is your religious preference?

- ○ Protestant (e.g., Baptist, Lutheran, etc.)
- ○ Catholic
- ○ Jewish
- ○ Muslim
- ○ Non-denominational
- ○ None
- ○ Other:

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #34 - Question

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Employment (check all that apply):

- ☐ Employed full-time
- ☐ Employed part-time

- [ ] Unemployed NOT due to a disability
- [ ] Unemployed due to a disability
- [ ] Retired
- [ ] Full-time student
- [ ] Part-time student
- [ ] Full-time homemaker

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

Item #35 - Question

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Which category would describe your family income, from all sources, before taxes last year?

- ○ Below $9,999
- ○ $10,000 - $19,999
- ○ $20,000 - $29,999
- ○ $30,000 - $39,999
- ○ $40,000 - $49,999
- ○ $50,000 - $59,999
- ○ $60,000 - $69,999
- ○ $70,000 - $79,999
- ○ $80,000 - $89,999
- ○ $90,000 - $99,999
- ○ $100,000 - Above

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break

~~Item #36 - Question~~

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~~Please indicate if you are willing to be considered for a follow-up telephone interview, which will ask additional questions about your experiences.~~

~~Note: Not all participants will be asked to participate in the interviews. Individual participants and couples may be considered for the interviews, but both spouses/partners do not have to agree to an interview to be considered.~~

- ○ ~~No, I do not want to participate in an interview~~
- ○ ~~Yes, I am willing to participate in an interview (please specify your NAME, MAILING ADDRESS, EMAIL ADDRESS, AND PHONE NUMBER below)~~

~~Further comments about your response:~~

insert the following here:

scale | multi-choice | ranking | semantic differential | short answer | header | page break | load page

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Closing Page Survey Properties

Closing Statement

DEBRIEFING STATEMENT

Thank you for participating in the study "My Kid Has More Chromosomes Than Yours!": The Journey to Resilience and Hope in Parenting a Child with Down Syndrome." The primary purpose of this study was to identify the key resilience factors in families who have successfully navigated this difficult transition and provide important information and resources for families facing this journey in the future.

By completing this study, you have contributed to a project that will provide information to new parents with a child diagnosed with Down Syndrome. It is hoped that this information will assist families in coping with this life change and gain their own resilience on the journey.

If you have any questions about the study, or would like to receive a report of this research when it is completed, please contact Briana S. Goff, PhD at (785) 532-1490 or bnelson@ksu.edu or Nicole Springer, PhD at 806-742-5050 x 267 or Nicole.springer@ttu.edu.

Again, thank you for your participation!

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Preview Done

Appendix B - IRB Approval

KANSAS STATE UNIVERSITY | University Research Compliance Office

TO: Briana Nelson Goff
FSHS
343 K Justin

Proposal Number: 7972

FROM: Rick Scheidt, Chair
Committee on Research Involving Human Subjects

DATE: 11/02/2015

RE: Proposal Entitled, "The Parents of Children with Down Syndrome Study"

The Committee on Research Involving Human Subjects / Institutional Review Board (IRB) for Kansas State University has reviewed the proposal identified above and has determined that it is EXEMPT from further IRB review. This exemption applies only to the proposal - as written – and currently on file with the IRB. Any change potentially affecting human subjects must be approved by the IRB prior to implementation and may disqualify the proposal from exemption.

Based upon information provided to the IRB, this activity is exempt under the criteria set forth in the Federal Policy for the Protection of Human Subjects, **45 CFR §46.101, paragraph b, category: 4, subsection:** .

Certain research is exempt from the requirements of HHS/OHRP regulations. A determination that research is exempt does not imply that investigators have no ethical responsibilities to subjects in such research; it means only that the regulatory requirements related to IRB review, informed consent, and assurance of compliance do not apply to the research.

Any unanticipated problems involving risk to subjects or to others must be reported immediately to the Chair of the Committee on Research Involving Human Subjects, the University Research Compliance Office, and if the subjects are KSU students, to the Director of the Student Health Center.

203 Fairchild Hall, Lower Mezzanine, 1601 Vattier St., Manhattan, KS 66506-1103 | 785-532-3224 | fax: 785-532-3278 | k-state.edu/research/comply | comply@ksu.edu