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# Walden University

College of Social and Behavioral Sciences

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Jacqueline Del Fierro Avila

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> > Walden University 2017

## Abstract

Stress and Marital Satisfaction of Parents With Children With Fragile X Syndrome

by

Jacqueline Del Fierro Avila

MA, Walden University, 2015

MA, Webster University, 2008

BA, University of Texas at San Antonio, 2004

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Clinical Psychology

Walden University

February 2017

#### Abstract

Raising a child with a pervasive developmental disorder (PDD), particularly that of Fragile X Syndrome (FXS), is challenging, as it comes with parental stressors for both mothers and fathers. Research on these stressors has been limited to only the stressors that mothers of children with a PDD experience and has failed to thoroughly examine the experiences and stressors of fathers of children with a PDD, particularly that of FXS. Using Hill's ABC-X family stress theory, this quantitative research study investigated the effects of marital satisfaction due to the amount of shared childcare responsibilities and parental stress among the mothers and fathers of children diagnosed with FXS. This study also examined whether significant differences exist among these parents, who were recruited through the use of flyers, notices, and handouts that were randomly passed out to parents at the FXS Alliance of Texas located in the southwest region of Texas. Participants for this study were 128 parents of children with FXS, each of whom completed a demographic questionnaire, the Kansas Marital Satisfaction Scale, and The Sharing of Childcare Responsibilities Scale and Parental Stress Level Scale. An independent samples t test and multiple linear regression statistical analysis was employed. The results of the study indicated that parental stress associated with the amount of shared childcare responsibilities accounted for a significant degree of the variance in marital satisfaction. Yet the study did not find a significant mean difference in the level of parental stress that was experienced uniquely across gender. Potential social changes may include future development and improvements in treatment, therapeutic approaches, and predicted outcomes in efforts to enhance parental stress interventions so as to improve stress-related outcomes for parents of children with FXS.

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#### Dedication

This body of literature is dedicated to my family, beginning with my husband, David, and my two precious girls, Yesenia and Clarissa Mia. David, without your support, continuous motivation, and love, this journey would have been impossible for me. However, because of your help and the many times you played both roles as mommy and daddy, you made the impossible possible for me, and for that I am very grateful, I love you infinitely.

My second dedication is to my beautiful parents, Oscar and Herminia Del Fierro, for without your strength, guidance, encouragement, support, and sponsorship, my dream of completing my doctoral degree would only be that, nothing but a dream, but because of your everlasting love and unceasing belief in me, my dream (our dream) is becoming a reality. I love you both more than words could ever say, thank you both.

My third dedication is to the rest of my family: my siblings, nieces, nephews, and in-laws, for you were all an inspiration to me and your love and support have been beyond anything I could have ever imagined. I hold every single one of you dear in my heart, and I am truly grateful for you and all your words of wisdom and praise to help me get through this difficult and challenging academic journey. I love you all very much.

I also dedicate this dissertation to the loving memory of my grandfather, Americo Garza (27 December 1924 – 05 November 2016). This dissertation is also dedicated to all the families who have a child diagnosed with Fragile X Syndrome for whose benefit this research was conducted.

Finally, to our Lord Jesus Christ, for without you, none of this would have ever been possible.

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# Chapter 1: Introduction to the Study

# **Background**

Raising a child with a developmental disorder consists of many challenges that most parents of typically developing children do not encounter. According to Ellis and Hirsh (2000), parents of children with a pervasive developmental disorder face significant trials with each new child's developmental stage, which results in increased levels of stress. To begin with, parents often struggle with learning about their child's diagnosis, and the process it entails to even begin assimilating it can be quite overwhelming and stressful (Ellis & Hirsch, 2000). In an extensive research of the literature, I found that the stress levels of parents of children with a pervasive developmental disorder are significantly higher due to numerous stressors in comparison to parents of typically developing children (Beckman-Bell, 1991; Beckman-Bell, 1981; Dyson, 1993; Fisman & Wolf, 1991; Johnson et al., 2003; Pisula, 2011; Poop, Robinson, Britner, & Blank, 2014; Woodman, Mawdsely, & Hauser-Cram, 2015). In addition, as research has indicated, parental stress may be due to a number of nonspecific, reoccurring, and significant challenges associated with the responsibility of taking care of their disabled child (Pisula, 2011). The research available also suggested that parental stress may significantly differ across gender due to the manner in which mothers and fathers manage and cope with their stress (Pisula, 2011). However, despite the parents' resources to manage their stress, more often than not, their stress ends up affecting their marital relationship (e.g., Johnston et al., 2003; McCarthy, Cuskelly, Kraayenoord, & Cohen, 2006). Additionally, a number of studies have compared parental stress affecting marital satisfaction with regard to certain developmental disorders like autism, and Asperger's syndrome.

However, there are limited studies dedicated to parental stress due to childcare responsibilities affecting marital satisfaction among parents of children diagnosed with Fragile X Syndrome (FXS). Therefore, my intention was to explore and investigate how marital satisfaction can be affected due to parental stress as a result of shared childcare responsibilities among parents of children with FXS.

According to Fernandez-Carvajal et al. (2009), FXS affects 1 in 2,500 individuals, and it has many similarities to mental retardation and intellectual developmental disorders. This is because it is the result of a gene mutation known as the Fragile X Mental Retardation-1 gene that blocks the production of the Fragile X Mental Retardation Protein (FMRP; Hagerman, 2006). When this occurs, the brain does not go through its many significant developmental growth changes, which then causes severe emotional and intellectual disabilities. For example, Hagerman (2002) explained that individuals with FXS tend to experience impairment in executive functioning and neurological impairment and have behavioral and communication problems. There are also physical characteristics that are commonly found in individuals with FXS, like long face, pointed ears, and soft skin. FXS is also known as a form of mental retardation, as it is characterized by an X chromosome as a single gene disorder that is abnormally susceptible to damage by folic acid deficiency (Sherman, 2002). It is a rare genetic condition that may cause a range of developmental problems to include but are not limited to intellectual, learning, emotional, and cognitive impairment (Sherman, 2002). Additionally, it is estimated 1 in 8,000 females are diagnosed with FXS, while 1 in 4,000 males are diagnosed with FXS (Right Diagnosis, 2014). However, males are more

severely affected in comparison to females as they portray severe developmental delays in speech and language, which is commonly more evident by the age of 2 (Right Diagnosis, 2014).

Moreover, the research found in this area mostly addresses exploring parental stress, family functioning, and child development (White & Hastings, 2004). However, research in parental stress, specifically examining it across gender, is very limited (Poop et al., 2014; Woodman et al., 2015). Therefore, as Poop et al (2014), and Woodman et al (2015) have suggested, additional research in this area may specifically help explore the demands of childcare responsibilities that parents (across gender) endure when raising a child with a developmental disability (Poop et al., 2014; Woodman et al., 2015). Long (2009) described that parents of children with a pervasive developmental disorder experience challenges that parents of typically developing children normally do not experience. For example, parents of disabled children struggle with searching and finding appropriate resources and community based programs for their child; they also worry about their child's developmental growth and progress and have to face the demands of their child's overt behavioral problems (Long, 2009). Children with an intellectual or pervasive developmental disorder also experience certain behavioral characteristics like social anxiety, social avoidance, irritability, and repetitive motor behaviors that cause significant stressors for parents (Abbeduto, Brady, & Kover, 2007). This is why research in this area has been mostly dedicated to examining such stressors that not only parents of disabled children experience but also that families, communities, and educational systems typically face.

There is also an abundance of research that has addressed the adverse effects that increased levels of stress of parents of children with disabilities experience, like anxiety, depression, family disruption, parenting self-efficacy issues, and cognitive appraisal problems (Bitsika & Sharpley, 2004; Eisenhower, Baker, & Blacher, 2005; Kuhn & Carter, 2006; Sharpley, Bistskika, & Efremidis, 1997; Wanamaker & Glenwick, 1998). Other research dedicated to this area includes but is not limited to investigating the effects of parental stress among parents of children with developmental disabilities and its relationship with poorer mental health, increased social anxiety, marital discord, and increased likelihood of divorce (Brobst, Clopton, & Hendrick,, 2009). The research in this area has addressed many variables as previously stated; however, one significant variable that lacks attention is with shared childcare responsibilities and parental stress, specifically investigating it across gender that may or may not affect marital satisfaction.

Furthermore, this variable is significant to explore as Ki and Joann (2014) concluded in their study that parents' childcare responsibilities is one major stressor associated and related to parents' marital satisfaction among parents of children with general disabilities in Hong Kong. To further explain, Ki and Joann (2014) found that childcare responsibilities and perceived stress among parents of disabled children were significant predictors of marital satisfaction. Therefore, in this study, I investigated the effects of all three variables among parents of children with FXS (across gender), as no study of this nature has been conducted before, and according to Ki and Joann, the correlations of these three variables in Western culture is significant to explore, as their results were limited to the population of Hong Kong.

Childcare responsibilities is a significant factor to consider when exploring parental stress because parental stress may be associated with the high demands of taking care of a disabled child, which includes but is not limited to medical decision making, financial burdens, treatment planning, and social involvement with community based support programs (Asberg, Vogel, & Bowers, 2008). Thus, parents who have a disabled child often describe their experience with raising their child as stressful (Asberg et al., 2008; Rogers & Hogan, 2003). In fact, Rogers and Hogan (2003) further explained that the stress of such parents can have a reciprocal effect on other family members. Therefore, it is important to examine the parents' experience and level of stress when raising a child with a developmental disorder, as parenting stress is highly associated with family and marital discord (Dyson, 1991, 1997; Fisman & Wolf, 1991; Frey, Greenberg, & Fewell, 1989; Gallagher, Beckman, & Cross, 1983). This will in turn shed some light and add to the body of professional knowledge with regard to parental stress and pervasive developmental disorders in order to adequately treat and manage parents' increased levels of stress.

Studying this phenomenon will also help delineate the stress differences found across gender that many researchers have attempted to explore but have failed to do (Jesser, 2003). Many researchers have studied stress levels among mothers of disabled children (Jesser, 2003); however, not much research has been dedicated to studying the stress levels of fathers of disabled children. However, it is noteworthy to explore such differences in stress levels as that itself could help provide an indication of how parental stress can result in marital dissatisfaction for both fathers and mothers of children with

developmental disorders.

Jesser (2003) explained how significant the research in this area is, especially with regard to parental stress and marital satisfaction as families, mental health professionals, parents, community based programs, and educational systems can highly benefit from such studies. However, despite the gap in the literature, there are limited studies focusing on families of children with pervasive and intellectual developmental disorders, parental stress, and marital satisfaction. In fact, for the purpose of this study, no literature was found about parents of children with FXS, parental stress, and marital satisfaction, even though this intellectual developmental disorder has received much attention within the past decade. Therefore, in this study, I attempted to determine the relationship (if any) between FXS, childcare responsibilities, parental stress, (specifically across gender), and marital satisfaction in an effort to add to the literature and promote mental health care for both mothers and fathers of children with FXS.

The effect of raising a child with FXS creates different parenting experiences for both mothers and fathers, which is why examining the stress levels across gender is significant to best facilitate treatment planning, community support, and an overall understanding in this area. Researchers have indicated that most families with children with a pervasive or intellectual developmental disorder tend to ignore family functioning and its dynamics when providing services, as most of the focus lies on the disabled child (Hadadian, 1194). However, it is suggested that such assistance and treatment planning should be focused more so on the entire family system rather than just the disabled child (Hadadian, 1994; Krauss, 1993). This is because mothers in previous studies became the

aim of such research; however, a father's experiences and parental stress should also be considered as that in itself may be the cause of significant increased stress levels for mothers, resulting in marital discord (Krauss, 1993; Crowley & Taylor, 1994). Crowley and Taylor (1994) further suggested that fathers' experiences should also be considered in studies about parental stress and marital satisfaction among parents of children with disabilities, as examining the sources of fathers' parental stress may add to the body of professional knowledge regarding family functioning. This is logical, as only looking at the mothers' experience of raising a child with a developmental disorder or disability limits the study as only one family member's experience is taken into account when examining the dynamics of the entire family.

Most families with children with an intellectual or pervasive developmental disorder experience some sort of challenge or difficulty as they adjust to the new dynamics of the family system (Harris, 1984; Krauss, 1993). Thus, it is not surprising that both mothers and fathers of these disabled children tend to experience elevated stress levels than parents of typically developing children. In addition, due to the increased levels of parental stress each parent faces, it is more common that these parents also face some sort of marital discord or dissatisfaction. Rodgers (1998) explained that when parents tend to experience elevated stress levels, a psychological spillover effect occurs, which is when another person's stress becomes problematic for the whole family system. When a psychological spillover occurs, familial problems begin to occur, which can include but are not limited to the following: problems between parents and their

nondisabled child, problems between parents and other family members, marital dissatisfaction, marital separation, or divorce and financial hardships (Jesser, 2003).

In conclusion, investigating and exploring parental stress across gender to include mothers and fathers of children with pervasive developmental disorders will enhance the knowledge of family functioning and its dynamics, as most researchers have neglected to include the fathers' experiences and perceived stress levels. This in turn will also open up the scope of study to better understand the significant impact of how parental stress of both parents can affect marital satisfaction, affecting the overall dynamics of the family. According to Krauss (1993) and Mulson, Caldera, Pursely, Reifman, and Huston (2002), there is a positive correlation between family discord due to the emotional state of both parents affecting their children. Mulson et al. further suggested that parenting stress is one of the many reasons family systems are disrupted, which ultimately has an effect on the overall functioning of not only the family but also with the development of the disabled child. Therefore, this study will not only enhance the body of literature pertaining to parental stress, marital satisfaction, and FXS but will also enhance the body of literature pertaining to family dynamics and family functioning among families and parents with children with pervasive developmental disorders.

#### **Problem Statement**

Byrne (2014) and Chapman (2013) explored and investigated the parental stress among parents of children with developmental disabilities in comparison to parents of typically developing children. They found that parents of children with an intellectual or developmental disorder experience at least twice as much stress as measured by the

Parental Stress Index, as their scores were mostly above the 85<sup>th</sup> percentile in comparison to parents of typically developing children (Byrne, & Chapman). Other researchers found that parents of children with disabilities, in general, experience increased levels of stress as compared to parents of typically developing children (e.g., Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Haung, Chang, Chi, & Lai, 2014; Johnson et al., 2003; Oelofsen, 2006; Webster, Majnemer, Platt, & Sheyell, 2008). Numerous researchers have also explored different variables affecting parents of disabled children, resulting in increased levels of stress like treatment planning, finding appropriate community based programs and services, facing their child's overt behavioral problems, marital discord, and encountering new and unexpected challenges with their child's developmental and intellectual growth (e.g., Brobst., 2009; Civick, 2008; Myers, Mackintosh, & Goin-Kochel, 2009; Perry, 2004; Weber, 2011). The American Psychiatric Association (2013) also reported significant predictors of stress among parents of disabled children that may result in elevated stress levels related to, but not limited to, learning about their child's disability or diagnosis, limited family and social support, and restricted patterns of child's behaviors. The research in this area has gone above and beyond studying and identifying such stress variables, and while researchers have extensively examined the parents' stress levels of children with disabilities in comparison to parents of typically developing children, limited research still exists focusing on stress levels across gender. More specifically, despite the extensive research in this area, there is limited research focusing on investigating parental stress across gender, particularly looking at parents of children with FXS.

Another area that lacks research is investigating the stressor of shared childcare responsibilities among parents of children with FXS. There are a few studies addressing FXS, but not much research has been established specifically looking at parental stress due to shared childcare responsibilities (Ki & Joanne, 2014). Ki and Joanne (2014) were some of the few researchers who investigated shared childcare responsibilities as a stress variable affecting marital satisfaction among parents, and no researchers have specifically examined this variable among parents of children with FXS. Therefore, the literature in this area could be expanded upon by precisely examining how stress levels of parents differ with regard to their shared childcare responsibilities and how that may or may not affect their marital satisfaction. Ki and Joann further explained that these variables have not yet been considered as indicators of marital satisfaction, in particular in Western culture; thus, the intention of this study was to add to the gap in the literature with regard to parental stress affecting marital satisfaction due to shared childcare responsibilities among parents of children with FXS.

# **Purpose of the Study**

The purpose of this quantitative research study was to examine more in depth the stressor of shared childcare responsibility that parents of children diagnosed with FXS experience. Also, I investigated if such stressor (shared childcare responsibility) differs among them (across gender) and how that may or may not influence their marital satisfaction. Therefore, in the quantitative research study, I examined and compared parental stress as it relates to the sharing of childcare responsibilities and marital satisfaction of parents of children with FXS.

In addition, I investigated the relationships among parental stress, shared childcare responsibilities, and marital satisfaction and examined how mothers' and fathers' perception of stress differs and how that may or may not impact their marital satisfaction. This research study enhances the body of knowledge in this area and furthers the understanding of mental health professionals, clinicians, psychologists, and the like about the differences of gender stress as it relates to parents' shared childcare responsibilities and marital satisfaction.

## **Research Questions and Hypotheses**

According to the problem statement and purpose of the study, it is my intention to address the following research questions:

RQ1: How does the perceived level of stress around shared childcare responsibilities of mothers and fathers of children with FXS differ?

 $H1_0$ : There are no statistically significant mean differences between mothers' and fathers' parenting stress levels due to their shared childcare responsibilities, as measured by the shared childcare responsibilities scale.

 $H1_a$ : There are statistically significant mean differences between mothers' and fathers' parenting stress levels due to their shared childcare responsibilities as measured by the shared childcare responsibilities scale.

RQ2: What is the relationship between the level of stress of parents of children with FXS and the amount of shared childcare responsibilities and marital satisfaction?

 $H2_0$ : The level of stress of parents of children with FXS will not significantly predict marital satisfaction, as measured by the level of marital satisfaction.

 $H2_a$ : The level of stress of parents of children with FXS will significantly predict marital satisfaction, as measured by the level of marital satisfaction.

H3<sub>0</sub>: The amount of shared childcare responsibilities of parents of children with FXS will not significantly predict marital satisfaction, as measured by the level of marital satisfaction.

H3a: The amount of shared childcare responsibilities of parents of children with FXS will significantly predict marital satisfaction, as measured by the level of marital satisfaction.

#### **Theoretical Framework**

Hill's (1966) family stress theory guided and served as the foundation for this study, as I investigated parental stress among parents of children with FXS due to their shared childcare responsibilities that may or may not affect their marital satisfaction. The stressful life event of raising a child with a developmental disability could either affect marital satisfaction negatively or positively. Moreover, the quality of family relationships could be affected by the parent's level of perceived stress as it relates to the caring of the child with a developmental disability.

Hill's (1966) family systems theory of family stress has been used to further understand marital outcomes and to help predict the functioning of families based on those marital outcomes. Karney and Bradbury (1995) further discussed how this theory is able to expand on the events that married couples endure that may impact a couple's

marriage. This theory also describes how stressful life events within a family system could create an imbalance or disturbance within that family system (Lavee & Sharlin, 1996). For instance, Hill studied family reactions to stressful life events by incorporating the ABCX model. The ABCX model is composed of (A) the stressful life event leading to (B) the effects of such stressor on the family system, which then leads to (C) the interpretation of the life event by family members, leading to (X), the produced outcome (Hill, 1966). This theory is also supported by Karney and Bradbury in which family members adapt to the life event in order to preserve the family system. However, if the family members produce an unwanted or negative outcome, then such life event (the stressor) may lead to marital dissatisfaction (Karney & Bradbury, 1995). This theory could very well be adapted and related to the life event and stressor of mothers and fathers raising a child with a developmental disability, specifically, a child with FXS. For example, (A) the child with FXS may (B) interrupt family cohesiveness, leading to (C) interpretation of the life event, either negative or positive, leading to (X) the outcome, which depends on how the family perceives the life event (child diagnosed with FXS) and how well they manage it (by having community and social support, therapy, and financial stability in place). Karney and Bradbury further suggested that the family who is unable to adapt to the stressful life event of raising a child with a developmental disability is more likely to have marital discord and marital dissatisfaction.

### **Nature of the Study**

The intention of this study was to ultimately add to the body of knowledge and to lay a foundation for future research regarding the investigation of marital satisfaction across gender due to parental stress as a result of shared child care responsibilities among parents of children with FXS. Furthermore, because research in this particular area is quite limiting, this study also serves as a foundational, informational-based gathering study to help identify how parental stress may vary across gender and affect marital satisfaction due to shared childcare responsibilities.

The research methodology design and statistical analysis that was appropriate for this research study is that of a quantitative research design, using a multiple linear regression analysis and independent samples *t* test. The stress levels of parents of children diagnosed with FXS due to their sharing of childcare responsibilities was explored and compared in an effort to identify if it has an effect on their marital satisfaction. The sampling strategy for this research study was probability sampling, specifically that of stratified sampling. Frankfort-Nachmias and Nachmias (2008) suggested a stratified sampling strategy is normally used to help ensure the sample selected at random is representative of the population. In addition, this type of sampling strategy allowed the selection of participants from mothers and fathers of children diagnosed with FXS. Because I investigated the effects of shared childcare responsibilities on parental stress and its relationship to marital satisfaction across gender, having a stratified sampling method was the most appropriate. Stratified sampling

allowed me to investigate the effects of parental stress, shared childcare responsibilities, and marital satisfaction of both mothers and fathers of children diagnosed with FXS.

The participants of this study met certain qualifying criteria first in order to be eligible for the study. The parents or subjects of this study needed to have a child between the ages of 2 and 12, be legally married, and have had the child living with them for at least 6 months. The participants could be the child's biological parent, step-parent, or primary caregiver, and their child was required to have a diagnosis of FXS given by a medical doctor, physician, psychiatrist, psychologist, or other mental health qualified professional. The study consisted of both males and females, and they could be of any level of education, socioeconomic status, age, and ethnic background.

Because the purpose of this study was to investigate and gain a better understanding of how parental stress, the independent variable (IV) and the sharing of childcare responsibilities, the independent variable (IV) affects and may be related to marital satisfaction, the dependent variable (DV) among parents of children diagnosed with FXS, I used three scales, one for each identified variables. The scales used in this study were the following: The Kansas Marital Satisfaction scale, measuring marital satisfaction, The Shared Childcare Responsibilities scale, measuring the shared childcare responsibilities, and The Parent's Stress Level scale, measuring the level of stress of parents of children with FXS. In addition, a demographic questionnaire was administered online to parents willing and interested in participating in the study. The following data were collected pertaining to each participant: their child's gender, age, and medical diagnose. Furthermore, information about the parents was collected, as this information

served as the covariates being measured in the study, which included the parent's gender, age, socioeconomic status, parent's level of education, race/ethnicity, and number of years married.

Moreover, the sharing of childcare responsibilities was measured using the sharing of childcare responsibilities scale (Goff, Mount, & Jamison, 1990). The marital satisfaction scale was used to measure the level of marital satisfaction of spouses as used in previous research, which is the Kansas Marital Satisfaction scale (Fowers, 1991; Schopler, Reichler, & Renner, 1986). Lastly, the parent's stress level was assessed by a scale that was used in similar research by Baxter, Cummins, and Yiolitis (2000) that includes measuring the parent's stress level with regards to seven sources of stress on a 7point Likert scale (Ki & Joanne, 2014). The seven sources of stress evaluated are the following: (a) accompanying the child to training in any one type of early intervention class or training center, (b) domestic training with the child, (c) allocating time between child care and work or housework, (d) guiding the child to learn, (e) handling the emotions and behaviors of the child, (f) the differences between the development of their child and that of other children of the same age, and (g) other people's view of their child care (Baxter et al., 2000). All instruments used are valid and reliable instruments as indicated in previous studies (e.g., Baxter et al., 2000; Flowers, 1991; Ki & Joanne, 2014). In addition, their psychometric properties were tested using the data collected for this particular study.

#### **Definition of Terms**

For the purpose of minimizing any confusion and ambiguity related to any misunderstandings of the language used in this study, as Cooper and Schindler (2003) suggested, the following terms have been defined:

Fragile X Syndrome (FXS): FXS is a genetic disorder that causes several developmental problems, including learning disabilities and cognitive impairment. FXS is caused by a mutation in the inherited X-linked chromosome (Hagerman, 2006). Most severe symptoms are more common in males than in females and are mostly evident by the child's delayed speech and language skills by around age 2 (Hagerman). Other symptoms include but are not limited to mild to moderate intellectual disability, increased levels of anxiety, hyperactivity, overt behavioral problems, and impulsive reactions. Additional physical features and characteristics associated with FXS that may be evident in males more so than females are a long and narrow face, large pointed ears, a prominent jaw and forehead, unusually flexible fingers, flat feet, and in boys macroorchidism (enlarged testicles) after puberty (Hagerman).

Marital satisfaction: Cao, Jiang, Li, Hui Lo, and Li (2013) assessed marital satisfaction in their study by using the Evaluating & Nurturing Relationship Issues, Communication & Happiness scale. This scale provided information regarding the couple's marital satisfaction by examining 11 factors that couples strongly believe are the basis and foundation of their marital satisfaction. They include personality compatibility, the couple exchange, conflict resolution, economic arrangements, leisure activities,

sexual life, children and marriage, the relationship between friends and relatives, and the role of equality and belief consistency.

Parental stress: Saloviita, Italinna, and Leinonen (2003) explained that parental stress among parents of children with disabilities differs in both mothers and fathers, as they described mothers' stress to be associated with the overt behavioral problems of their child, while fathers' stress is associated with the experienced social acceptance of their child. However, Morris (2000) described parental stress to be caused by a number of predictors that produces endangerment to the individual's psychological, emotional, and physical well-being due to a lack of internal and external resources. In addition, for the purpose of defining parental stress, it is significant to point out that there are a number of studies identifying and defining parental stress as a physiological, psychological, and emotional response to a life crisis or demand due to lack of resources, coping skills, and social support (e.g., Delmabo, Chung, & Huang, 2011; Donavan, 1988; Theule, Wiener, Rogers, & Marto, 2011; Walker, 2000).

Shared childcare responsibilities: Budig and Folbre (2004) explained that parenting and childcare responsibilities are not necessarily a specific set of activities involving the care of a child, rather it is a state of being that is continuous and neverending. Along these lines, McCubbin and Thompson (1991) described it to be a set of basic attributes that describe and explain how a family system typically appraises, operates, or behaves. Additionally, for the purpose of this study, shared childcare responsibilities include examining the following: accompanying the child to training in any one type of early intervention class or training center, engaging in a domestic training

with child, allocating time between child care and work or housework, guiding child to learn, and handling the emotions and behaviors of the child (Baxter et al., 2000).

## **Assumptions**

It is significant to point out five basic assumptions in this study, as they pertain to validity of the study. It was first assumed all participants were fully knowledgeable about the significance of the study and they understood the terms and conditions related in the confidentiality form. Second, it was assumed all participants were truthful and honest with regard to responding to the questionnaires and surveys provided via the website, and to encourage honest participation, all participants remained anonymous throughout the study. Third, it was assumed the participants in the study understood the implications within the study, and by their own admission, they volunteered for the study. Fourth, it was assumed the participants reviewed and acknowledged the qualifying criteria and by their own admission agreed and adhered to the study's requirements, as fully qualified participants in order to participate in the study. Lastly, it was assumed the questionnaires and surveys used within the study accurately measured the constructs being investigated.

# **Scope and Delimitations**

Parental stress and marital satisfaction due to shared childcare responsibilities are key variables to explore among parents of children with developmental disabilities.

However, despite the intensity of research available with regard to each of these variables, parental stress, marital satisfaction, and childcare responsibilities, no literature was found combining all three variables. Therefore, the focus of this research was to investigate all three variables and its effects among parents of children with FXS.

The population of interest for this study was limited to the parents of children diagnosed with FXS. However, it is significant to point out that no one variable can directly affect, manipulate, or change the outcome; therefore, other homogeneous variables were considered in this study. The homogeneous variables accounted for in this study are the following: the parent's gender, age, socioeconomic status, level of education, race/ethnicity, and number of years married. These variables needed to be accounted for, as no one variable can determine the success, failure, or presence of a relationship. Furthermore, even though the research methodology and design for this study was outlined specifically, the end result may apply to parents of children with other intellectual or pervasive developmental disorders. Finally, another delimitation of the study is that the questionnaires all used a Likert scale, which limited the participant's responses, meaning other conclusions could have been reported but were not, due to the nature of the questionnaires.

#### Limitations

This research study was limited to the parents of children diagnosed with FXS who by their own will took part in this study. The study consisted of completing certain questionnaires, and the participants were informed of the significance of their honesty when completing the questionnaires. To encourage honesty and truthfulness when completing the surveys, they were also informed that their identity and answers would be kept confidential and remain anonymous. Another limitation for this study is with regard to the possible lack of reliability of the instruments used to collect the data.

In addition, since all data collected were via a website, the website needed to

remain secure, be easily understood, be easy to navigate, and be user-friendly. In addition, regardless of the sampling strategy, the results of this study may not be generalized to the greater population, as other variables need to be taken into consideration. For example, only legally married parents of children with FXS participated in this study, and separated and divorced parents of children with FXS were excluded from this study. However, regardless of this study's limitation, the findings may contribute and add to the body of knowledge and literature for not only mental health professionals but also for the parents and families of children diagnosed with FXS.

# **Significance of the Study**

Research in the area of marital satisfaction, parental stress, and shared childcare responsibilities among parents of children with developmental disorders is rather limited. However, according to the literature, parents of children with developmental disorders have increased levels of stress, and thus have a greater chance of divorce (Baker-Erizen et al., 2005; Hartley et al., 2010; Moh & Magiati, 2012; Myers et al., 2009; Ramisch, 2010; Sander & Morgan, 1997). The parents of disabled children are faced with numerous stressors and challenges, one being childcare responsibilities that may very well increase their stress, resulting in marital discord. Thus, I focused on marital satisfaction as the dependent variable, in hopes to find some type of relationship between parenting stress caused by shared childcare responsibilities. In other words, I report on the effects of parenting stress on marital satisfaction due to shared childcare responsibilities among parents of children with FXS.

My intention is to contribute to the existing literature and professional knowledge about the relationship of parental stress and marital satisfaction due to the amount of shared childcare responsibilities among parents of children with FXS. This is because most research done in this area does not explore or take into consideration all three variables, especially among parents of children with FXS. In fact, upon the extensive search done, no research study has been conducted regarding the effects of parental stress and marital satisfaction due to childcare responsibilities. Furthermore, by examining such variables, one may begin to understand how shared childcare responsibilities might contribute either positively or negatively to marital satisfaction. Additionally, this study might bring on a new level of understanding with regard to how parents' marital satisfaction could have a spillover effect which, in turn, may affect their parent-child relationship (Erel & Burman, 1995). Moreover, no researcher to date has investigated or compared the mothers' and fathers' stress levels due to childcare responsibilities among parents of children with FXS; thus, I attempt to close a gap in the existing literature pertaining to parental stress and FXS.

This study will also provide theoretical implications, add to the body of knowledge, and lay a foundation for future research of how different sources of stress may affect marital satisfaction among parents of children with FXS, and make direct across gender comparisons within the mother-father dyads. Moreover, I attempt to further the understanding of how and why specialized programs and therapeutic assistance is essential to promote and provide to parents with children diagnosed specifically with FXS. This study will also contribute to improvements in treatment,

therapeutic approaches, and predicted outcomes and help develop more effective stress-reducing interventions in order to improve stress-related outcomes among parents with children diagnosed with FXS. Lastly, this study will help lay the foundation for future research regarding the relationships with exploring parental stress (across gender), shared childcare responsibilities, and marital satisfaction as variables among parents of children with other intellectual and pervasive developmental disorders.

### **Summary**

To summarize, Chapter 1 was an overall view of the research study, which includes the background of the study, purpose of the study, problem statement, research questions, theoretical framework, nature of the study, assumptions, delimitations, limitations, and significance of the study. The sampling strategy used in this study was clearly defined, and information pertaining to the qualifying criteria each participant was expected to adhere by was also included. The participants were all parents of children diagnosed with FXS, and they all solely volunteered for the study. The surveys and questionnaires the parents filled out via the website created and provided was expected to be answered truthfully, which was also solely based on their integrity. In addition, all data collected were kept confidential and remained anonymous as no identifying information was asked of the parents. Finally, the data collected in this study yield results that add to the body of professional knowledge and literature in the area of parental stress, marital satisfaction, childcare responsibilities, and FXS.

Following this chapter is Chapter 2, which provides an in-depth review of the literature about FXS, parental stress, marital satisfaction, and shared childcare

responsibilities. The extensive literature review done in these areas also provides a thorough understanding of how these variables can have a cause and effect relationship with one another, and more importantly, how they can all influence one another.

## Chapter 2: Literature Review

## **Introduction to the Literature Review**

The parent-child relationship with parents of children with developmental disabilities changes with each new child's developmental stage, and according to Ellis and Hirsh (2000), adapting to those changes could be quite challenging. Parents often struggle with making those adjustments, as the process of assimilating the child's developmental changes and adjusting to them are among some of the many stressors parents face (Ellis & Hirsh, 2000). The process of parents adjusting to their child's diagnosis and developmental stages could be quite overwhelming and stressful (Ellis & Hirsh, 2000). In fact, a number of studies have shown that the stress levels of parents with children diagnosed with developmental disabilities to be much higher than parents with typically developing children (Ellis & Hirsh, 2000; Johnston et al., 2003).

Parental stress may be the result of any one complex set of nonspecific, reoccurring, and significant challenges associated with the responsibility of taking care of the child (Pisula, 2011). The parental stress level is also associated with the type of developmental disability the child is diagnosed with (Pisula, 2011), and a number of researchers have examined and compared the stress levels among mothers of children with different developmental disabilities (e.g., Down syndrome, Asperger's syndrome, autism, and FXS; White & Hastings, 2004). However, very few researchers have examined FXS and parental stress (across gender). Additionally, current studies (e.g., Poop et al., 2014; Woodman et al., 2015) have addressed family functioning and child development but have neglected to examine the additional demands of childcare

responsibilities that parents endure due to the raising of their child with a developmental disability.

Moreover, Long (2009) suggested that raising a child diagnosed with a developmental disability often brings on challenges that parents raising a typical developing child will not commonly face, such as recruiting and finding community based programs and services, tackling significant behavioral problems, carrying out additional childcare responsibilities, and facing new stages of developmental growth with uncertainty. Furthermore, considerable evidence has suggested that behavioral characteristics like anxiety, social avoidance, isolation, irritability, repetitive motor behaviors, high activity level, and difficulty coping with unexpected changes to be evident in children diagnosed with a developmental disability (Abbeduto et al., 2007). Because of these demands, researchers have been dedicated to examining the effects that raising a child with a developmental disability has on parents, families, communities, and school programs.

Current researchers have also been focused on documenting the adverse effects that raising a child with a developmental disability has on parents, to include but not limited to depressive and anxiety symptoms (Bitsika & Sharpley, 2004; Eisenhower, et al., 2005; Sharpley; et al., 1997), family disruption (Eisenhower et al., 2005), parenting self-efficacy, coping strategies, and cognitive appraisal (Kuhn & Carter, 2006; Wanamaker & Glenwick, 1998). Other researchers have focused on examining parental stress among parents with children with developmental disabilities and its associations with poorer mental health, a decrease in leisure time, and the likelihood of divorce when

compared to parents with typically developing children (Brobst et al., 2009). In addition, Brobst; et al. (2009) described that having a child with a pervasive developmental disorder may contribute to marital dissatisfaction resulting in divorce. Research in this area suggested that there are many significant factors contributing to marital dissatisfaction that can lead to the possibility of divorce, like lack of resources for the disabled child (e.g., Brobst et al., 2009; Ramisch, 2010). Nonetheless, having a child diagnosed with a developmental disorder can certainly add to the many stressors that parents may already be enduring, which can result in marital dissatisfaction (Brobst et al., 2009).

However, despite the immense research on sources of parenting stress and marital satisfaction and dissatisfaction among parents of children with developmental disabilities, there is limited research specifically targeting FXS and its associations with parental stress and marital satisfaction (e.g., Johnston et al., 2003; McCarthy et al., 2006), specifically looking at the parent's shared childcare responsibilities (Ki & Joanne, 2014). This variable is significant to explore among this population as Ki and Joanne (2014) concluded that parent childcare responsibilities is one major stressor associated and related to parents' marital satisfaction among parents of children with general disabilities in Hong Kong. To be more specific, the linear regression analysis used in their study demonstrated the amount of shared childcare responsibilities and perceived stress among parents as significant predictors of marital dissatisfaction (Ki & Joanne, 2014). They looked at one major source of stress, the shared childcare responsibilities and its associations with marital satisfaction of parents of children with general disabilities. Ki

and Joanne found shared childcare responsibilities to be correlated with marital dissatisfaction among parents of children with disabilities.

Moreover, parents who have a child diagnosed with a developmental disorder often use the term *stressful* as it relates to their parenting experiences (e.g., Brobst et al., 2009; Ki & Joanne, 2014). This stress is often overlooked by mental health professionals and supporting staff, which in turn may positively or negatively affect the parents' marital satisfaction (Asberg et al., 2008). Thus, many researchers have dedicated time and money in an effort to investigate the sources of stress and marital satisfaction among parents of children with disabilities to include autism spectrum disorders and mental retardation (Asberg et al., 2008). Additionally, there is limited research on how the parents' stress levels differ across gender based on their shared childcare responsibilities and its associations with marital satisfaction, specifically among parents of children diagnosed FXS. The research found in this area has addressed marital satisfaction and perceived stress among parents of disabled children; however, it does not delineate the difference between mothers and fathers as it pertains to their shared childcare responsibilities (Asberg et al., 2008).

Raising a child diagnosed with FXS can cause elevated stress levels for the parents, which can potentially affect not only the parent's mental health well-being but also that of their family (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Rogers and Hogan (2003) explained how stress of one family member can have a reciprocal effect on other family members. Asberg et al., (2008) further suggested that parental stress can be associated with the children's behavioral problems, which can negatively affect the child-

parent relationship. There are many other stressors affecting parents of children diagnosed with FXS to include but not limited to the financial burden (Baker-Ericzen, Frazee, & Stahmer, 2005), lack of leisure time (Sanders & Morgan, 1997), and the permanency of the disorder itself (Higgens, Bailey, & Pearce, 2005). Often, behavioral conduct or lack of in children with FXS may also increase parents' stress levels (Higgens et al., 2005). Higgens et al. (2005) further explained that disruptive behaviors can limit the parent's willingness to socialize, which can result in limited social support and understanding, leading to increased feelings of frustration, irritability, resentment, and feelings of hopelessness (Higgens et al., 2005; Rodriguez, Morgan, & Geffken, 1990). Additionally, researchers have suggested other variables associated with the parent's increased levels of stress include but are not limited to the lack of attention with other family members, like that of their other typically developing children and their spouse (Ramish, 2010).

## **Literature Search Strategy**

The literature review was conducted mostly through the Walden University online library. However, in order to begin the research, most of the relevant articles were first downloaded from Google Scholar. Upon conducting the search using certain key words, like *Fragile X Syndrome*, *parental stress*, and *marital satisfaction*, the research itself became more feasible as many articles became available. These articles then became downloadable through the Walden online library by using PsychArticles, PsycINFO, and EBSCO host. Additionally, I was able to download a large number of significant dissertations related to the study. Most of the dissertations downloaded were found

through the dissertations and theses searchable items that consisted of a database that contained a full text of dissertations and theses written by doctoral level candidates and graduates.

The search strategy incorporated for this literature review included but was not limited to narrowing the research found down to the last 5 previous years. However, some earlier articles were also obtained and used throughout this study, as most of the information pertaining to FXS began in 1969, which was the initial year FXS was first identified (Turner, 1996). Moreover, when the number of articles pertaining to this study subject's matter became too overwhelming, numerous, or imprecise, certain search key words or Boolean commands were used. This included using search limiters, index fields, and a combination of all using keywords like *parental stress and Fragile X Syndrome, marital satisfaction and shared childcare responsibilities, childcare responsibilities and pervasive developmental disorders*, and other pervasive developmental disorders, like Autism and Asperger's, and parental stress and childcare responsibilities. The scope of literature ranged from Angell (1936) to Woodman et al., (2015).

## **Theoretical Foundation**

The theoretical foundation that guided this study is Hill's ABC-X theory, as it specifically helped align the stressful life event of raising a child with a developmental disability and its implications of parental stress leading to positive or negative marital satisfaction. This theory provided an overview of how a specific life event (e.g., having a

child diagnosed with FXS) affects the family (e.g., parental stress), which in turn may or may not affect marital satisfaction.

# Hill's (1949) ABC-X Theory

Hill (1949) structured his theoretical framework by first examining three variables, that later became known as the ABC variables. The X variable, which was incorporated later, explained the overall outcome of the ABC variables or the overall outcome of the significant life changing event. The first three variables of Hill's theory are what ultimately determined the X variable or the overall consequence, also known as the crisis due to the family event or stressor (Komarovsky, 1940). The variables are described as (a) the family event itself, leading to (b) the experience of family managing the event, or the resources available for the family to face the event, and (c) the manner in which the family views and the manner in which they actually experience the event.

Hill's theory was formalized in 1949, and it was based off of the results of 135 interviews from Iowa families during the Second World War (Angell, 1936; Komarovsky, 1940; Koos, 1946). Based on the results of these interviews, Hill determined, the A variable would define the hardships these families endured during the Second World War due to the deployment of their loved ones. Furthermore, Hill described the hardships to be a change in their family income, housing inadequacies, relocation of home due to the loss of a family member, illness of a family member, rebellious behavior of their child or children due to loss of family member, and mother having to work to fulfill the lack of income, and support provided by father before having to deploy (Waller & Hill, 1951).

The second variable, the B variable, consisted of how the family managed the deployment of their family member. Hill further described 10 qualities that could help the family better adjust to this stressor of having their family member deploy. The 10 qualities include (a) history and familiarity of the stressor, (b) having adequate knowledge and control over finances, (c) flexibility with mothers taking the fatherly role (e.g., mothers having to leave their homes to go work), (d) all family members being in agreement with the change of roles and with one another performing their family duties, (e) family's ability to put selfish acts to the side, focusing only on the best interest of the family (e.g., performing selfless acts to benefit the whole family), (f) being prideful of family, (g) having trust, love, and unity present with the family system, (h) equal sharing of family responsibilities, (i) equal distribution of family control and decision making, and (j) strong affection of family members among all members of the family (Boss, 1987).

The third variable, the C variable, described the manner in which the family perceived that event or stressor. Waller and Hill (1951) suggested that the manner in which the family viewed the stressor or life changing event depended on the family's subjective feelings about the actual event and manner in which they coped with it. The family reacted to the situation how they knew best, which depended on the family's familiarity of the event and their experience with it, and on the manner in which they managed that event, which was also highly dependent on the availability of their resources; for instance, if the family was financially stable, if they supported one another, and if they truly cared for and loved one another (Waller & Hill, 1951).

The X variable was later incorporated by Hill to reflect the crisis or end result of the family event or stressor (Koos, 1946). Hill (1949) defined a crisis to be "any sharp or decisive change for which old patterns are inadequate" (p. 51). Hill believed that once the family experienced that life changing event, they would either survive it or be defeated by it. However, if the event itself became a crisis, then the family would follow a negative path in which less enthusiasm for family would be evident, more resentment towards one another would be present, and more family conflict would emerge. However, he described this stage to be temporary as long as an agreement between the family members could be made (Hill, 1949). If this were the case, then the family dynamics could improve, and less and less tension and disagreement between them would be apparent (Boss, 1987). Additionally, the X variable represented the stage in which the family could see either a positive or negative outcome. This means that if the crisis itself would be taken and accepted in an adequate manner, then adaptation to the life event could occur. However, if the crisis were to be managed inadequately, then the end result could be devastating, with unrewarding situations where the family members would not be able to adapt to the change, causing an increase in tension and failure in problem-solving that could end in unbearable anxiety for all members of the family (Caplan, 1964).

In short, Hill's ABC-X theory paved the way for many other family stress theories and laid the foundation for most family stress research and theories that have evolved during the past 45 years (Burr & Kleins, 1994). Most research on family and life changing events have emerged due to Hill's ABC-X theory, as these variables provide a

basis with regards to how families may or may not react, manage, and adapt to these life changing events and stressors (Burr & Kleins, 1994). In addition, these past years of research that have focused on family systems have incorporated the variables of the ABC-X model in one way or another, as it provides the foundation for the manner in which families manage certain life changing events (Burr & Kliens, 1994).

The research itself in this area has grown and changed dramatically; however, most research found in family systems simply expands on these variables, without minimizing the importance of these variables. Also, the research dedicated to family stressors and life changing events simply looks at these variables further and is explained best by examining the A variable as the stressor itself, the B variable as the family's availability of resource(s), the C variable as the family's perspective on the life changing event, and the X variable as the outcome or end result of that event.

## **Research Based Analysis and Previous Studies**

Knapp (2005) incorporated the Hill's ABC-X theory to expand on her research by looking at how family systems, especially that of marriage can be affected by stressful life events, such as raising a child with autism. Knapp explained Hill's ABC-X theory grounded her research as it laid the foundation for how external and internal events within families and married couples can either negatively or positively influence the outcome of the family or marriage itself. An example of a research study incorporating Hill's ABC-X theory is with exploring marital relationships due to the impact of raising a child with Autism as explained in Knapp's research. In this study, Knapp examined the

implications and impact raising a child with autism has on the quality of marital relationships.

In her study, Knapp (2005) examined how the raising of a child with autism predicts marital outcomes. According to Knapp's study, Hill's ABC-X model consisted of examining how a stressful life event (A), can lead to the family's way of managing that life event (B) which then produces the manner in which the family interprets or perceives that event (C), leading to the crisis, or outcome of that life changing event (X). To better explain, Knapp points out how the child with autism (A) may interact with family cohesiveness (B), which then leads to the family's interpretation of the event (C) followed by the stress related to raising a child with autism and availability of positive resources, like cohesiveness, which then determines the (X) the outcome that can either be positive or negative based on the family's interpretation of that stress (being the child with autism).

Knapp's (2005) study has paved the way for similar research in which stressful life events are examined that could potentially influence the outcome of family systems which includes but is not limited to parental stress and marriages. Therefore, the theoretical perspective guiding this particular study, is that of family systems, specifically that of Hill's family stress theory, using the ABC-X Theory. Hill's family stress theory was expanded on using the ABC-X model to better explain the functioning of families, while looking at marital outcomes (Hill, 1958, 1966). Thus, the theoretical framework chosen for this study is Hill's ABC-X theory since the stressful life event of raising a child with a developmental disability could either affect marital satisfaction negatively or

positively. In addition, the quality of family relationships could be affected by the parent's level of perceived stress as it relates to the caring of their child with a developmental disability.

This research study specifically incorporated Hill's ABC-X theory to help define how family stress, particularly that of parental stress can be utilized to predict the functioning of families, while mainly looking at marital outcomes (Hill, 1966). Karney and Bradbury (1995) suggested this theory has been used in similar studies to help expand on stressful life events that married couples experience which can ultimately affect their marital outcome (e.g., Knapp, 2005; Lavee & Sharlin, 1996). Their studies suggested that the manner in which the families react to the stressful life event can very well determine the crises or end result of that event which can ultimately affect parental stress and marital satisfaction. Therefore, this theory relates to the present study as it will help answer the following research questions: a) how does the perceived level of stress of mothers and fathers of children with FXS differ due to their shared childcare responsibilities and, b) what is the relationship between the level of stress of parents of children with FXS and shared childcare responsibilities and marital satisfaction? This theory will guide this research study as it will help look at the life event and stressors of mothers and fathers raising a child with FXS and how it relates to or affects parental stress that could either positively or negatively affect marital satisfaction, because of their childcare responsibilities.

To better explain, (A) the life changing stress event, being that of the child diagnosed with FXS may (B) interrupt family cohesiveness or the family's status quo

which leads to (C) the manner in which the family interprets that event, which then leads to (X) the final outcome, which all depends on how they perceive that life changing event, that is highly dependent on the resources available to them, and the manner in which they manage and share their childcare responsibilities. The final outcome once again could either be positive or negative, such as developing a stronger and deeper bond between the family or the contrary, developing further family discord leading to marital dissatisfaction.

# Conceptual Framework: Development of the ABC-X variables The A Variable

The A variable as previously described was initially developed as consequence of Hill's (1949) research with regard to family separation during the Second World War. The stress these families endured at that time resulted in many hardships according to Hill's research (Hill, 1966). In 1965, Hill revisited such hardships and identified four specific conditions in which families could relate and identify with regard to these hardships. Hill further described these hardships as a) dismemberment or loss of a family member, b) accession or addition of an unexpected family member, c) demoralization or loss of family unity, and d) a combination of all three conditions (Hill, 1966). However, years later, Lazarus, Averill, and Opton (1974) revisited such conditions and classified these stressors in more general terms. Lazarus et al's., research, concluded three situations needed to be present within the family system in order for the life event to be considered an actual *stressful* life event. The three situations are: a) the uniqueness of the actual environmental demands, b) the emotional response of the family or individual

experiencing such demands, and c) the effective or ineffective coping skills portrayed by the individual or family experiencing such demands (Lazarus et al., 1974).

Another study that incorporated and delineated Hill's A variable is that of Boss's (1987) research. Boss examined Hill's (1949) study about the family's stress events and concluded that there are many different types and categories of stressors and stressful events, and there are no specific conditions or classifications for them. Boss (1987) suggested the family's stressful life events all depend on the manner in which the family identified with that specific situation. In other words, the more prepared the family is with facing that dilemma the lesser the stress level is for that particular family. Boss (1987) further believed that the family had all the control and the A variable ultimately signified the actual stimulus or starting point of the challenge itself thus, the family itself had all the control over the actual outcome of that specific life changing stressful event. Boss's (1987) further suggested in his research that the A variable or actual stressful event could potentially predetermine the outcome of the family, all depending on how they managed the stress endured by that specific event. For instance, it could be classified as excessive stress, optimal stress or deprived stress (Selye, 1980). In short, the response of the distressed family highly depended on the specific endured stressor, which was what ultimately determined the manner in which the family coped with it, also known as the second key variable of Hill's ABC-X model.

#### The B Variable

Hill described the "B" variable as the manner in which the family coped with regards to the demands of the actual stressful event. Furthermore, Hill (1949) was one of

the first researchers who used the term resource to describe the type of coping strategy and the manner in which the family could best manage that stressor. Before Hill however, Cavan and Ranck (1938) and Koos (1946) examined a specific family's way of coping with stressful life events by suggesting the family come into an agreement with regard to the family's roles and goals. It was suggested the greater the agreement between the family members, the greater the cohesiveness of the family (Cavan & Ranck, 1938). With the evolvement of this research, Hill was then able to adopt and further develop the variable "B" as the availability of the resource itself to better cope with the stressful life changing event. Hill (1949) incorporated the "family's mutual agreement" research conducted by Cavan and Ranck (1938) and Koos (1946) into his own research to better understand family unity, bonding and coping mechanism in order to improve the family's flexibility and understanding when experiencing a specific life stressor. As a result, the resource variable "B" emerged and was later elaborated on by many other researchers (e. g., Foa & Foa, 1974; Otto, 1963; & Pilisuk & Parks, 1983). On a side note, Hill (1949) was first identified and credited as the one researcher who identified family's integration, cohesiveness, flexibility and adaptability as resources for managing family's undue stress caused by a life changing event.

## The C Variable

The "C" variable as described by Hill (1949) determined the manner in which the family experiences or perceives that stressful event. Hill (1949) further described this variable was what ultimately determined the end result or outcome of the life changing event as it signified the manner in which the family views that stressor and how they

identify with it. This variable specifically looked at how the family responded to that stressor, both personally and spiritually.

Waller and Hill (1951) specifically examined this variable and defined it as the family's physical, emotional and spiritual response to the family stressor which includes but is not limited to the family's culture and financial status as well. The authors suggested the cultural aspect has to do with the manner in which the family interprets their specific family conduct or beliefs about what their specific family conduct ought to be. Hill further stated the family's subjective belief of their culture far outweighed the actual definition of family culture as described by other researchers (Waller & Hill, 1951). This subjective definition also led the family to its particular belief of what they actually considered a stressful event or a life changing event within their family system. Waller and Hill (1951) further explained the family responded to the crisis in the manner in which they knew best which was according to the availability of their resources, financial status, values and previous experiences with similar situations.

With this being said, Waller and Hill (1951) gave meaning to resources as described by variable "B" by dividing it into two levels: primary and secondary appraisal. The primary appraisal is the family's overall view and perception of available resources that includes their financial status, and emotional and physical well-being. The secondary appraisal is the family's evaluation of how well they can actually manage the crisis based on the availability of their resources. Boss (1987) further investigated such factors and added two significant elements to Waller and Hill's definition of the "B" variable. Boss (1987) suggested not only was emotional, physical and financial status

significant factors in defining resources within the family system but also boundary ambiguity and the degree of denial. To better explain, boundary ambiguity was defined by Boss (1987) as the uncertainty of who is actually part of the family system and who isn't, for instance, who can actually voice an opinion and who cannot. Boss related this concept to family members who particularly were lost in war and who might not be present physically within the family however, were very present emotionally within that family.

Lastly, just like with variable "B", other researchers further investigated and elaborated on the "C" variable, suggesting it actually should be broken down into three different levels and not 2, which includes giving the resources situational meanings, family identity with roles, rules and ritual and family's interpretation of the world around them that is outside of their family (Patterson & Garwick, 1994). To conclude the "C" variable is essential to the understanding of how families view and perceive their crisis and ultimately helps explain the meaning the families actually give to their life stressful event.

## The X Variable

In Hill's (1949) ABC-X model, the "X" variable was identified as the actual crises or the stage in which the outcome of the stressor occurred. A crisis situation in this case, also known as a life changing event as defined by Koos (1946) is any type of situation in which role patterns are changed. Furthermore, the effects of such crises could change the family's actual role patterns or the manner in which the family performs. However, these role patterns could be easily manipulated depending on the individual's

view of the outcome. For instance, if anyone member's expectation is not met, then the usual pattern for the family has to be changed as that pattern is now distorted, thus the family needs to develop new role patterns to best manage the crises or outcome of the stressor (Hill, 1949).

A study by Caplan (1964) further analyzed this concept of the "X" variable or crisis situation and explained such crises can only occur when four specific elements are present. First, a stressful event has to occur in which the family responds to with specific problem-solving techniques. Second, the family's specific problem-solving technique fails however, the event itself is still causing undue stress for the family. Third, the family's undue stress increases which causes the family to explore other failing problem-solving techniques and fourth, the crisis is then identified as unbearable due to failure of problem-solving techniques thus, an increase in anxiety and stress is now even more evident than ever before (Caplan, 1964).

It is also significant to point out, there are many other studies that help delineate and further explain the "X" variable as crises, and discusses other types of elements needing to be present (e.g. Boss & Greenberg, 1984; Burr, 1994 and McCubbin, Cauble, Comeau, Patterson and Needle, 1980). These studies are all significant to the history and development of the "X" variable as they not only expand on this concept but provide another view of how the final outcome is derived from, all depending on the manner in which the family views and manages their life event or crises situation. Finally, the studies described above provide the foundation of how family stress can affect family cohesiveness, which depends on the severity of the stressor and the manner in which they

best know how to manage and cope with it. Which is why, Hill's ABC-X model is the theory that grounds this study as it provides an overview of how having a child diagnosed with FXS (a life changing event) can affect the family causing undue stress for them which in turn may or may not affect marital satisfaction due to their childcare responsibilities.

## Fragile X Syndrome

Fragile X Syndrome (FXS) affects approximately 1 in 2,500 individuals (Fernandez-Carvajal et al, 2009) and it is caused by a mutation in the Fragile X Mental Retardation-1 (FMR1) gene that hinders the production of the Fragile X Mental Retardation Protein (FMRP) (Hagerman & Hagerman, 2002; Hagerman, 2006). This protein is essential for the growth and expansion of the brain and it is quite significant for the progression of the brain's functioning and maturation (Huggins & Haggerman, 2004; Tassone et al., 1999). When the production of this FMRP protein is hindered then a certain neurobehavioral profile is evident in individuals which includes hyperactivity, intellectual disability, impairment in executive functioning, and communication difficulties (Hagerman & Hagerman, 2002; Hessl, Wang, Schneider et al., 2009). These behavioral and neurological impairments can be associated with Autism, making FXS one of the most known monogenic conditions under Autism Spectrum Disorder (Hagerman, 2008). Furthermore, approximately 4-8% of Autism diagnoses can be traced back to FXS, thus, FXS has been studied as a genetic disorder that has similar features that are shared across all etiological subtypes of autism (Abrahams & Geschwind, 2010; Hagerman, 2008 & Hagerman, Au & Hagerman, 2011).

However, even though FXS has similar features and symptoms associated with Autism, FXS has its own set of diagnostic criteria which includes but is not limited to social anxiety, gaze avoidance, impairment in executive functioning, like impulse control and lack of attention and social communication impairment (Abrahams & Geschwind, 2010, Hagerman & Hagerman, 2002; Kaufmann et al., 2004). Furthermore, Cohen, Pichard and Tordjman (2005) attested, FXS does not reflect "true" Autism as it only reflects similar features and behaviors. Moreover, research and observational studies indicate significant differences in Autism related cases when compared to FXS cases, like children with FXS actively avoid eye contact whereas Autistic children seemed indifferent and are not actively avoidant to social gaze (Cohen et al., 2005).

Other research studies have reported distinguishable differences in profiles associated with Autism and FXS as measured by autism diagnostic assessments and tools and other symptom like-rating scales (Cohen et al., 2005; Dissanayake, Bui, Bulhak-Paterson, Huggisns & Loesch, 2009). With this being said, FXS was first recognized as a single-gene, X-chromosome linked disorder and is one of the most common hereditary causes of Mental Retardation (Turner, 1999). FXS is caused by an expansion of the CGC trinucleotide sequence (mutation) on the X-chromosome and individuals with greater than 200 repeats are classified as having the full mutation of FXS (Center for Disease, 2006). On the other hand, individuals with approximately 55-200 CGG repeats are characterized as having permutation of FXS and those that have less than 55 repeats are placed within the normal range. The individuals classified with the full mutation experience an alteration on the FMRI gene on the X chromosome which then results in a

reduction of that protein. As stated previously, this reduction of protein is highly important for the full development, growth and functioning of the brain and as a result, lack of this protein causes FXS in individuals (Tassone et al, 1999).

When discussing FXS it is significant to point out its many characteristics that can be present in an individual diagnosed with FXS that may be obvious in any which way or form that is either physically, behaviorally, intellectually or socially visible. Some physical characteristics include but is not limited to low muscle tone, large ears, flexible bones, a long face, flat feet, recurrent ear infections and seizure disorders (Hagerman & Cronister, 1996). Behavioral characteristics includes hand-flapping, hand-biting, avoidant behavior and avoidant eye contact. Other intellectual and social characteristics include but is not limited to speech and language delays, delay of fine and motor skill development, attentional difficulties and mental retardation (Hagerman & Cronister, 1996). Most mental retardation known FXS cases fall within the moderate to severe range of mental retardation thus, these individuals experience significant developmental delays due to limited brain growth which is caused by the lack of production of the FMRP protein (Hagerman & Cronister, 1996).

#### **Parental Stress**

## **Definition of Parental Stress**

Parental stress is defined by a number of predictors that exists between the person and the environment that exceeds their available emotional, physical, and psychological resources, resulting in an endangerment to their own well-being (Morris, 2000). In addition, such predictors are often times determined by the negative perception parents

often times give to that particular situation. Saloviita, Italinna, and Leinonen (2003) explained parental stress in mothers of children diagnosed with a pervasive developmental disorder are provided by the negative perceptions they have with the behavioral problems of their child, while the fathers parental stress is associated with the experienced social acceptance of their child.

Donavan (1988) on the other hand, defined parental stress as the parent's response to life situations and high demands to life crises or events that involves both physiological and psychological reactions that can either be instantaneous or delayed. In another study, Delambo, Chung, and Huang (2011) defined parental stress as the emotional response between the environment and availability of resources to include social support and coping mechanisms to problem situations. Whereas, Theule, Wiener, Rogers, and Marto (2011) reported parenting stress as the emotional and psychological response parenting involves with regard to the child's physical, emotional, psychological, intellectual and developmental demands.

Lastly, parental stress as explained by Walker (2000) is the "relationship between the person and environment which is dynamic, bidirectional and mutually reciprocal" (p. 2). These definitions of parental stress for the most part discuss parental stress as not being able to adequately cope with life situations and also discuss the difficulty of life situations of parents with children with a pervasive developmental disorder that are stretched to their limits, resulting in increased levels of emotional and psychological distress., affecting their overall well-being.

## Parental Stress and Fragile X Syndrome

Parenthood as research findings indicated can bring significant amounts of gratification, happiness, enjoyment and pleasure (e.g. Eibach, & Mock, 2011; Kenrick, Griskevicius, Neuber & Schaller, 2010; Wolf, Noh, Fisman & Speechley, 1989). However, there are many challenges and experiences that can definitely take a toll on the parent as well, causing them undue stress (Wolf et al., 1989). In fact, many research studies have found parents experience significant amounts of stressors that are linked to a variety of factors, like financial burden, relocation, new addition to the family (birth) or death (Latson, 1995). These stressors are significant factors that not only increase the levels of stress for parents but can also alter their emotional and psychological wellbeing. In addition, parent's increased anxiety and stress levels can also be related to their concerns for how they are raising their child, their child's physical safety, financial stability and their child's normal developmental and intellectual growth (Latson, 1995). Latson (1995) further suggested parents typically experience increased levels of stress when their child does not perform to the best of their abilities and are often times disappointed by the outcome: their child failing.

On the contrary, it is particularly more challenging and stressful for the parents when their child behaves differently than other children and are not growing and developing like other typically developing children (Gupta, 2011). When a parent's child is challenged and diagnosed with a pervasive developmental disorder like Mental Retardation or FXS, the parents stress level tends to be significantly higher than parents compared with typically developing children. This in part has to do with their child not

being able to meet not only their expectations but also their family's and community's expectations. Therefore, it is of no surprise, that parents of children with developmental disorders tend to experience higher levels of parental stress when compared to parents of typically developing children (Laston, 1995). This finding was later researched by Grupta (2011) as he investigated the relationship of increased parental stress levels in parents with children with disabilities, such as Attention Deficit Hyperactivity Disorder, parents of children with a learning disability, parents of children with asthma and parents of children with HIV-infected children. Additionally, in his study he examined and compared parental stress in parents with typically developing children. Grupta (2011) collected and analyzed the data received from the Parenting Stress Index Scale and concluded the parents of children diagnosed with a Attention Deficit Hyperactivity Disorder and learning disability reported increased levels of stress when compared to parents of children diagnosed with asthma, parents of HIV-infected children and parents of typically developing children.

However, for the sake of this study which exams parental stress of parents of children diagnosed with FXS, it is significant to point out that much of the literature in this area is quite limited as most of the research conducted in this area has been done within the last decade or so (Low, 2013). Most research in this area includes literature about adults and older children diagnosed with FXS that focuses solely on specific behavioral problems such as their hyperactivity, inattention, temperament and aggression (Hagerman, 2002; Sullivan et al., 2006). Other problems addressed within the body of the literature discusses precursors to behavioral problems associated with FXS, like

autistic-like behaviors, anxiety, shyness, avoidant behavior and difficulties with internalizing and externalizing problems (Hatton et al., 2002; Sullivan et al., 2006; Kau et al., 2000). Thus, the literature in this area, specifically looking at parental stress of parents of children with FXS is limited and remains unclear.

Additionally, the limited research in this area suggested parents with children with FXS are more stressed than parents with typically developing children as they report their children to be more active, less approachable, less sociable, less persistent, more avoidant and less adaptable (Roberts, Boccia, Hatton, Skinner and Sideris, 2006). A study by Shanahan et al., (2008) described parents with children with FXS reported that their child displayed increased levels of negative reactivity like, anger and sadness when compared to typically developing children. Other studies examining this area suggested the temperament of children diagnosed with FXS is significantly more different than other children diagnosed with other pervasive developmental disorders, like Mental Retardation and Autism (e.g. Kerby & Dawson, 1994). The Emotionality, Activity and Sociability Temperament Scales (EAS) was used in a study by Kerby and Dawson (1994) to assess individuals with FXS and the authors concluded these individuals were more withdrawn, cautious, less social and less active when compared to individuals in the control group.

Hatton, Bailey, Hargett-Beck, Skinner and Clark (1999) conducted a longitudinal study in which mothers rated their child's temperament over the course of 18 months.

The study compared 45 males, ages 47-88 diagnosed with the full mutation of FXS to that of a normal control sample. Over the course of the study, 102 maternal ratings were

collected. The mothers used the Behavioral Style Questionnaire (BSQ) that was used in a previous study (Carey & McDevit, 1978) to assess their child's temperament. The BSQ scores only ranged from 1-4 ratings and each mother of each group, including the control group was expected to submit a total of 2 assessments per child with an adequate rating of their child over the course of the 18 months. The authors concluded the mothers of the children with FXS rated their child as significantly more active, less flexible, less compliant, less sociable and less intense when compared to the normal control sample (Hatton et al., 1999). Once again, the literature found in this area is significant to this research study as it provides a greater understanding and view of what mothers of children with FXS rate their child as when compared to normal control groups. This study adds to the body of literature as it helps explain the higher levels of stress found in parents of children with FXS as evident by the ratings they give their child when compared to the ratings provided by parents of typically developing children.

In another study by Roberts, Boccia, Hatton, Skinner and Sideris (2006) the mothers of children with FXS between the ages of 1-11 years (mean= 4.11 years; SD= 2.07 years) were asked to rate their child's temperament and behaviors. These ratings were then compared to 31 typically developing children of the same age and ethnicity. The mothers of these children were asked to rate their child on the age appropriate form of the Carey Temperament Scales. The children ages 1-3 years were also rated using the Toddler Temperament Scale (TTS; Fullard, McDevitt & Carey, 1984), the children ages 3-7 used the Behavioral Style Questionnaire (BSQ; Carey & McDevitt, 1978) and the children ages 7-11 were rated using the Middle Childhood Temperament Questionnaire

(MCTQ, Hegvik, McDevitt, & Carey, 1982). The study concluded that the children diagnosed with FXS were rated by their mothers as being more active, less persistent, less adaptable and less attentive as compared to typically developing children of the same age group and ethnicity (Roberts et al., 2006).

Adding to the body of literature, Shanahan, Roberts, Hatton, Reznick and Goldsmith (2008) examined the relationship between behaviors, early temperament and negative reactivity in a small sample of boys with FXS ages 3 years (N=25). They compared the ratings provided by their parents to that of 64 typically developing children of the same age. The parents of these children in both groups were asked to rate their child using the Children's Behavior Questionnaire (CBQ; Rothbart, Ahadi, Hershey & Fisher, 2001) and the Childhood Autism Rating Scale (CARS; Schopler et al., 1986). The CBQ scale is geared for children ages 3-7 and it measures the child's temperament while the CARS measures the behaviors associated with the diagnosis of Autism which are also similar behaviors found in children diagnosed with FXS. The parents of these children were also asked to complete the Mullen Scales of Early Learning (Mullen, 1997) and the Laboratory Temperament Assessment Battery (Lab-TAB; Goldsmith & Rothbart, 1996). The results of their study indicated the males with FXS are indeed more active, less adaptable, less intense, less persistent, less social, and less approachable than the control group or that of typically developing children. Additionally, the boys diagnosed with FXS were rated as having difficulties displaying facial sadness, anger, ability to vocalize distress and bodily struggles as compared to the control group. In other words, the boys with FXS showed increased levels of negative reactivity when compared to

typically developing children as indicated by all measures used (Shanahan et al., 2008). In addition, their study also concluded an apparent increase of sadness in parents of children with FXS as indicated on the CBQ scale for boys with FXS when compared to the control group.

In another study conducted by Baker and McCal (1995) parenting stress of parents of children with Autism and other learning disabilities were investigated. Their study also included parents of typically developing children. However, their study included a limited amount of fathers' responses, thus, most of the information collected about parenting stress were derived from mothers and they suggested future research should be done to include fathers' responses.

In their study, Baker and McCal (1995) concluded that mothers of children diagnosed with Autism or other learning disabilities do experience higher levels of parenting stress when compared to mothers of typically developing children.

Furthermore, the mothers of children with these diagnoses reported their child for the most part were more demanding, irritable, less adaptive and less social than other typically developing children. The authors further suggested the mothers of children with Autism and other learning disabilities that displayed more problem behaviors like hyperactivity and aggression have higher stress levels when compared to mothers of typically developing children (Baker & McCal, 1995).

Yet another study by Davis and Carter (2008) examined parenting stress of mothers and fathers of children with Autism Spectrum Disorder. In their study, the authors concluded the mothers of children with an Autism Spectrum Disorder have

higher stress levels as compared to the fathers of these same children. The mothers reported to have more stress than the fathers as evident by the Parenting Stress Index-3 scales (PSI-3). The mothers' stress levels fell well within the clinically significant range as measured by the PSI-3 (David & Carter, 2008). In fact, the results indicated that one-third of the mothers reported to have higher levels of parenting stress than the fathers and most of the stress reported by the mothers were related to the parent-child relationship. In addition, half of the mothers reported to have elevated stress levels on the Parent-Child Dysfunctional Interaction domain, which was similar to the stress levels found in the fathers of children with an Autism Spectrum Disorder.

## **Parental Stress and Gender Differences**

Majority of the research dedicated to parental stress of parents with children with an intellectual or pervasive developmental disorder focuses on the mothers and not the fathers. This is so as research has found that in most cases where a family has a child with a developmental disorder, the mother typically ends up being the designated care taker (e.g. Baker-Ericzen et al.; 2005, Brobst et al.; 2009, Hastings, 2003; Taanila, Kokkonen & Jarvelin, 1996; Woodgate, Ateah & Secco, 2008). Additionally, research in this area indicated that due to the mothers taking on the majority of the parenting responsibilities, often times, they are the ones that have increased levels of parenting stress and the ones that are most likely to exhibit various forms of psychopathology problems (e.g. Brobst et al., 2009; Oelofsen & Richardson, 2006). This is evident in several studies that investigated the levels of parental stress among fathers and mothers of children with a development disorder. For example, Rivard, and Terroux (2014)

described the mothers of disabled children in their research reported to have less social support, increased levels of negative feelings, more emotional distress and tend to experience more daily struggles. Also, Baker and Heller (1996) reported that mothers of disabled children reported increased levels of stress due to the high demands of their child who exhibits externalizing behaviors. Webster-Stratton (1990) reported mothers who perceive their child with behavior problems tend to report higher levels of stress and are less enthusiastic and positive about their children.

Other studies that compared parental stress of mothers and fathers of children with a developmental disorder described mothers to have increased levels of stress than that of the fathers (Harris, 1984). Another study by Dumas et al. (1991) reported the child's externalizing behaviors is what highly influenced and predicted the stress levels among these parents however, mothers once again reported more increased levels of stress as compared to the fathers. However, these are only a couple of dated studies that discuss parental differences of stress among parents of children with developmental disorders. This is one area in which the research is quite limited however, the next few sections will discuss more in detail significant differences of parental stress and types of stressors experienced across gender, among both the mothers and fathers of disabled children.

## **Mothers**

Research pertaining to parental stress among parents of children with developmental disorders such as Autism, Asperger Syndrome, Down Syndrome and other Intellectual disabilities report that mothers generally do have increased levels of anxiety,

stress and depression than fathers do (Delambo et al., 2011; Gau et al., 2012; Hastings et al., 2005; Theule et al., 2011). In part, this notion has to do with mothers taking on the majority of the parenting responsibilities which involves them leaving their work and in essence losing their sense of self as they become consumed with their child's world (Gau et al., 2012; Gray & Holden, 1992). Due to the high demands of their child's care taking needs, these mothers often times have much less needed respite care in comparison to the fathers thus, they tend to emotionally and physically neglect themselves. This in turn, causes undue stress for them and as such, they experience higher levels of parental stress in comparison to the fathers who are able to physically remove themselves from that situation through the means of their work (Gau et al., 2012).

Hastings et al., (2005) study further examined this concept and found that maternal stress had a strong and positive relationship with the externalizing behaviors of the disabled child but no significant relationship was found between the externalizing behaviors of the disabled child and paternal stress. A more recent longitudinal study conducted by Barker et al. (2011) found a positive relationship between maternal stress, anxiety and depression and the disabled child's behavior problems as opposed and compared to the paternal stress, where no significant relationship was found.

This area of research as noted before is quite limited and dated however, the primary differences of parental stress among mothers and fathers of children with developmental disorders often lies with the mothers perception of their child's behavioral problems. Webster-Stratton (1988) studied these differences and they determined that mothers perceived more problems with their child than the fathers did and because of

such, their results from the Parenting Stress Index showed significant elevated scores as compared to the fathers. The mothers mean scores from the Parenting Stress Index indicated clinically significant stress for these mothers as their mean score equaled to the 95<sup>th</sup> percentile (Webster-Stratton, 1988). In another study, mothers of children with Down syndrome reported to have increased levels of stress in comparison to the fathers (Fisman, Wolf & Noh, 1989).

Other studies have reported mothers to have a higher level of parenting stress than fathers with children with disabilities that are both physical and psychological (Boyd, 2002; Fisman et al., 1989; Barker et al., 2011). Most research in this area has found that mothers of these children tend to score at the 90<sup>th</sup> percentile on the Parenting Stress Index, indicating acute distress (Boyd, 2002; Rodriquez & Murphy, 1997). The acute distress these mothers often times experience have to do with certain physical and psychological stressors that are related to the parenting demands of raising a child with a developmental disorder. Such stressors may include but are not limited to fatigue, depression, tension, social isolation, decreased self-worth, low self-esteem, lack of work and social goals, role restriction and couple/marital problems (Krauss, 1993; Fisman & Wolf, 1991; Frank et al., 1991; Tannila et al., 1996).

## **Fathers**

Sanders and Morgan (1997) reported fathers with children with Autism tend to experience increased levels of stress just as much as the mothers tend to experience it.

Additionally, the fathers in their study reported significant levels of depressive symptoms and stress however, when compared to other fathers of children with other developmental

disabilities, their stress levels and depressive symptoms were significantly lower (Sanders & Morgan, 1997; Hartley, Seltzer, Head & Abbeduto, 2012). Hartley et al. (2012) reported such differences are likely due to the unique stressors associated with their child's diagnosis of Autism and its particularities regarding this developmental disorder. It is also significant to point out that even though the fathers experience depressive symptoms, increased levels of stress and anxiety due to their child's developmental disorder, the levels of such still by far do not compare to that of the mothers. Hastings et al. (2005) reported that even though paternal stress was significant, most of the stressors experienced by the fathers weren't even directly related to their child's behavior, diagnosis or parenting demands. Their study concluded paternal stress was associated with their partner's depression level and depressive symptoms. In other words, the mother's level of depression and stress levels were significant predictors of the fathers' stress levels due to the mothers concern and caring demands for their disabled child (Hastings et al., 2005).

Furthermore, Hadadian (1994) suggested, that for the most part, paternal stress due to having a child with a developmental disability has not been thoroughly studied. Therefore, a gap in the literature regarding this issue still to this day exists, as most of the current research done in this area focuses on maternal stress. In fact, centuries ago, most research examined the association increased levels of stress of mothers has on fathers due to their disabled child (Cummings, 1976). Due to this reason, most of the research and support provided is geared for mothers of disabled children (Cummings, 1976).

Nonetheless, it is believed that even though the mothers and fathers stress levels differ,

due to their different familial roles, expectation and needs, the fathers still should be of focus, in order to provide them with the assistance and mental health care they need (Esdaile & Greenwood, 2003; Hadadian, 1994; Jesser, 2003; Krauss, 1993). It was suggested many domains be examined and researched regarding the fathers stress to include but not limited to their parenting demands, parent/child relationship, mother's emotional state, employment status of the mother, father's educational level, marital satisfaction, and child's diagnosis, age, behavior, and temperament (Dutra, 1999; Esdaile & Greenwood, 2003; Vetere, 1994).

If this research were to be delivered, perhaps, proper mental health care could be offered and provided for fathers of children with intellectual or developmental disorders to include treatment for increased levels of depression, stress and anxiety, and decreased levels of self-esteem, self-worth and marital satisfaction (Cummings, 1976; Jesser, 2003; Vetere, 1994).

## **Marital Relationship**

When parents experience the birth of their child, they tend to neglect one another, as most of their time and focus is dedicated to their new born. Hartley et al., (2008) explained many families go through this transition period and because of such, many parents have a higher risk of divorce up until their child's teenage years. Most research done in this areas suggests that the increased risk of divorce of these parents are more than likely due to the increased parenting demands and stress associated with raising a child (Hartley et al., 2008). However, these demands associated with parenting are diminished overtime as their child grows older, as they become more independent and

responsible. Parents with typically developing children can then focus and attend to their own needs to include but not limited to their marital relationship (Harris, 1984, Hartley et al., 2008).

However, this is not the case for parents with children with a developmental disorder. Harris (1984) and Hartley et al. (2008) explained children with a developmental disorder are highly dependent on their parents for an extended period of time, resulting in increased levels of stress in parents that subsequently affects their marital satisfaction. To better explain, Hartely et al. (2008) conducted a longitudinal study in which they studied 391 couples with a child diagnosed with an Autism Spectrum Disorder and 391 couples with a typically developing child. Their study suggested that couples with a child with an Autism Spectrum Disorder divorced twice as often as those couples with a typically developing child. In addition, the authors found that of those parents that divorced, 94.6% of them lived with their disabled child at home at the time of the divorce. However, it is significant to point out that Hartley et al. (2008) did not find any significant differences of marital satisfaction even if their disabled child was no longer in their home as they continued to worry about their child's well-being. In other words, regardless whether their disabled child lived at home or not, the parent's stress levels remained high due to the high demands and responsibilities of their child and because of such their marital relationship suffered (Harris, 1984 & Hartley et al., 2008).

The increased parental stress of raising a child with a pervasive developmental disorder in part has to do with the prolonged periods of time that raising such a child has on the parents itself (Hartely et al., 2008 & Hartley et al., 2012). Due to the demands of

raising a child with a developmental disorder the couple's relationship is what ultimately suffers and as such, couples with a child with a developmental disorder tend to experience decreased levels of marital satisfaction (Gorchoff, John & Helson, 2008; Hartley et al., 2008, Hartley et al., 2012). This concept in part has to do with the parents putting their child's needs first, before their own needs. Therefore, because of such, these parents tend to neglect one another, which can then result in decreased levels of marital satisfaction and increased levels of parental stress (Gorchoff et al., 2008).

This is also true of parental stress, when discussing and examining the severity of their child's diagnosis and needs. For example, if their child has more severe symptoms and requires more attention, the parents may attend to them first, putting everything else aside, including their marriage (Gorchoff et al., 2008; Hartley et al., 2012). These findings are consistent with the research completed in this area and for the most part, as research suggests, parents of children with pervasive developmental disorders experience increased levels of parental stress and have decreased levels of intimacy, resulting in marital dissatisfaction (Brobst et al., 2009, Gau et al., 2012; Taanila, Kokkonen & Jarvelin, 1996). To support this claim, a study by Brobst et al., (2009) suggested mothers of children with pervasive developmental disorders experience higher levels of parental stress due to their increased child's behavioral problems and decreased spousal support. In short, their study concluded the mother's stress levels are significantly correlated to their reduced marital satisfaction because of lack of support from their spouse or partner (Brobst et al., 2009).

Additionally, the authors Collins, Maccoby, Steinberg, Hetherington and Bornstein (2000) determined the quality of the marriage can also impact and affect the development of their disabled child. They further explained, there are several risk factors that can significantly affect the child's emotional, physiological, and psychological wellbeing. For example, having poor communication, family dispute, and marriage conflict and dissatisfaction can increase the likelihood of the child developing various forms of psychopathology.

Coie and Asher (1996) also examined several risk factors involving failure in marriages that may negatively influence the child's psychopathology to include but not limited to lack of affection with another, inadequate supervision of children, lack of involvement with children and parental stress. Their studies also determined that parents of children with disabilities tend to experience increased levels of marital distress and marital conflict thus, they are significantly challenged as their beliefs about parenting itself is altered. Their parenting beliefs and perception of their family dramatically changes which can then lead to a more functional or dysfunctional family unit (Coie & Asher, 1996). The authors further discussed the functionality of the family can then lead to an increase or decrease of the parent's marital satisfaction which can then significantly affect the child's growth and development (Coie & Asher, 1996; Li-Tsang, Yau & Yuen, 2001).

McStay, Trembath and Dissanavake (2014) investigated the parental stress among parents of children with Autism Spectrum Disorder and described the mothers stress is mostly due to the child's observed behaviors and their partner's depression whereas the

fathers stress is directly related to their child's perceived behaviors and lack of spousal attention and support. However, it was determined that mothers tend to rely more on their spouse for emotional support and they are more direct with regard to communicating this need to their spouse (McStay et al., 2014).

In another study Hartley et al. (2012) investigated 199 mothers of a child with a developmental disorder and their marital satisfaction over a seven-year span. Their study suggested that marital satisfaction of mothers decreased as their child's problem behaviors increased throughout the seven-year span. The authors further stated, it was common for the mother's stress levels to increase as well when their child's behavior problems became more evident resulting in a spillover effect into the marital relationship (Hartley et al., 2012). Their argument was with regard to how the high demands of their child took priority over their marriage resulting in increased levels of parental stress, affecting their overall marital relationship/ satisfaction. Hartley et al., (2012) described the child's behavioral, emotional and physical demands to be of priority for these mothers hence, their marital relationship for the most part suffered the consequences.

As a final note, this study mainly focused on the mothers' parenting stress levels affecting their marital satisfaction however, per the authors their intention was to also add to the body of literature of parental stress of both mothers and fathers of children with developmental disorders affecting marital satisfaction (Hartley et al., 2012). However, unfortunately, the fathers in this study were not closely observed, thus most information gathered were from the mothers of these children. In short, most research in this area focuses solely on the mothers' parental stress however, future research should be

dedicated to examining the effects of parental stress of fathers of children with development disorders (Hartley et al., 2012; Lecavalier et al., 2006; & Tomanik et al., 2004).

#### **Marital Satisfaction and Divorce Rates**

It is significant to point out that most of the research that described the experiences of parents with children with an intellectual or pervasive developmental disorder with regard to their couple satisfaction is quite limited. The literature review in this area is quite narrow however, by studying parental stress and marital satisfaction of parents of children with FXS, it can help us develop a better understanding of how parental stress differs across gender in efforts to better understand their specific individual differences. Which in turn, can provide us with new information pertaining to the importance of these couple dyads and their marital relationship/satisfaction.

With this being said, there is however, a small portion of literature that addresses the impact of parental stress on marital satisfaction that was studied over a century ago. For instance, Levinger and Huston (1990) study, described the overall life satisfaction of parents of diverse cultures with regard to their marriage. They found most parents rate their marital satisfaction as most important when evaluating their overall life satisfaction in comparison to other variables, such as work, health and number of children (Levinger & Huston, 1990). The parents in their study also discussed several factors that caused marital conflict and distress that resulted in marital dissatisfaction for them. One area that created the most conflict within their marriages was with regard to their role of parenting.

Jenkins, Simpson, Rasbash and O'Conner (2005) further expanded on Levinger and Huston's (1990) research and explained marital dissatisfaction are due to several predictors affecting their role of parenting such as increased child adjustment problems, and child's behavioral problems. This finding also coincides with Collins, Maccoby, and Steinberg, Hetherington & Bornstein (2000) research as they determined most couple / marital satisfaction is determined by the negative effects that stress has on each of the individual's emotional and physical well-being. The authors further suggested the most common causes of emotional and physical stress for marital couples included but is not limited to relationship problems leading to separation and divorce (Jenkins et al., 2005).

Brobst, et al, (2009) reported parents of children with developmental disabilities are challenged to find time to attend to both their disabled child and their partner.

Additionally, research in this area demonstrates parents who have a child diagnosed with a pervasive developmental disorder like Autism, FXS and Asperger's Syndrome experience higher levels of stress which can ultimately affect their couple's relationship, impacting their marital satisfaction (Brobst et al., 2009). To be more specific, Brobst et al (2009) explored and compared marital satisfaction in 25 couples with children with Autism to that of 20 couples' marital satisfaction with typically developing children.

Their research indicated no significant differences among the two groups when examining their demographic variables. However, when investigating parental stress due to their child's behavioral problems, relationship satisfaction, respect for partner, spousal social support and commitment they concluded the parents of children with Autism reported significantly lower levels of relationship or marital satisfaction. When they

examined the parents' levels of social support, it was determined that parents with higher levels of social support experience less clinically significant stress than parents who reported lower levels of social support (Brobst et al., 2009). Their study also concluded parental stress in fathers of children with a pervasive developmental disorder to be significantly negatively correlated with total social support. Consequently, the authors found that in both groups, respect for one another were significant predictors of relationship/ marital satisfaction and it was determined marital satisfaction was less clinically affected in parents of children of typically developing children than in parents of children with a developmental disorder.

The divorce rate of parents of children with an intellectual or pervasive developmental disorder as research indicates are clinically significantly higher than parents of typically developing children. These differences are particularly more evident in parents with disabled children of all ages as compared to parents of typically developing children with children 8 years or younger (Hartley, Barker Seltzer, Greenberg, Floyd & Orsmond, 2010). The divorce rates of these parents are more critical when their typical developing child is younger than 8 years as compared to parents of disabled children whose divorce rates remain critical, at all times, regardless of their child's age (Hartley et al., 2010). To further explain, a longitudinal research study conducted by Hartley et al. (2010) compared the divorce rate of 406 parents of children diagnosed with Autism to that of parents with typically developing children. Their study concluded the divorce rate among these two groups remained the same up until their child reached to be 8 years old. In other words, once the typically developing child turned 8

years old, the divorce rate of these parents significantly decreased however, the divorce rate among parents of children with Autism remained the same throughout their study, even after their child with Autism aged. This is so, as one of the authors explained that parenting demands among parents with typically developing children begin to decrease for the most part once their child turns 8 years. However, the parenting demands of children with Autism of any age, or any other intellectual developmental disorder for that matter never seems to decrease. This in turn, can then lead to an increase of marital strain within their relationship, which often times results in divorce for these parents (Hartley et al., 2010).

The author further proposed that parents of children with Autism experience parental stress and marital dissatisfaction well into their child's adulthood and thus, marital strain may remain high in their child's later years (Hartley et al., 2010). Their study specifically noted that parents of typically developing children were less likely to divorce over the 8 year span (14%) than parents of children diagnosed with Autism (23%) (Hartley et al., 2010). Additionally, factors that influenced the divorce among these parents included but is not limited to the child's birth order, family cohesiveness, mother's age, mother's education level, number of children in the household and number of children in household diagnosed with an intellectual or pervasive developmental disorder (Hartley et al., 2010).

#### **Shared Childcare Responsibilities**

There are many significant studies dedicated to the complex measurements involving the responsibilities of the household and care work (e.g. Coltrane, 2000; Folbre

&Bittman, 2004; Kan et al., 2011; Sullivan 2013). However, there is only a limited amount of studies dedicated to the particularities involving parenting and childcare responsibilities (Lamb, Pleck, Charnoy & Levine, 1985). In fact, the authors argued despite the importance of this subject not much research in this area has been presented. Most research pertaining in this area has been focused on the implications of house work and care work, with regard to the actual obligations of maintaining a household, thus, the specifics and inferences of childcare responsibility has been neglected (Lamb et al., 1985).

Leslie, Anderson and Branson (1991) explained, this in part has to do with the characteristics that the concept of childcare responsibility itself presents and its complex methodological issues that may in part, not be adequately well understood. In another study, Budig and Folbre (2004) noted in their extensive review of parenting and childcare responsibilities that childcare and its responsibilities are not just a set of activities, rather they are a state of mind that are ongoing, and never-ending for parents. Thus, thorough research should be devoted not only to the category of childcare responsibility in general but also to the primary and secondary obligations of parenting across gender. However, despite these findings, current research in this area is limited nonetheless, there are several recent studies regarding parenting and childcare responsibilities (Goldberg, 2013; Perry-Jenkins, Newkirk, & Ghunney, 2013; Sullivan, 2013).

The care demands of children with intellectual and developmental disorders are significantly higher because the parent's workload and childcare responsibilities increases in such families as compared to families/ parents of typically developing

children (Little, 2002). In one study, it was determined maternal stress levels were directly tied to the high demands of childcare responsibilities (Johnson et al., 2003). The authors further suggested, this is especially true when the fathers are absent in the child's life, or are less involved in their child's care (Johnson et al., 2003; Milgram & Atzil, 1988). As a result, mothers are primarily involved in their child's welfare that includes treatment planning, making medical decisions, and planning for family gatherings and social engagements (Gray, 1993). With such childcare demands falling on mothers, it's no surprise, the mothers tend to feel abandoned by their spouse, resulting in decreased spousal support and marital satisfaction.

Tannial et al.'s (1996) research indicated due to decreased spousal support mothers of children with developmental disorders tend to have increased levels of maternal stress. Tannial et al.'s (1996) further reported due to the unequal distribution of childcare responsibilities, and increased levels of maternal stress, mother's marital satisfaction also tends to affected. Furthermore, Willoughby and Glidden (1995) suggested if parental stress and childcare responsibilities are equally disturbed, marital satisfaction could potentially also increase for both mothers and fathers. Their study noted that the equal sharing of parental stress, childcare responsibilities and burden of caretaking among parents can very well help alleviate the stress carried by just the mother or the father. This is so, as it creates a feeling of team work, which in turn decreases both the mothers' and fathers' feelings of loneliness, isolation and separation within the family system.

### **Role Expectations**

Parental stress among parents of children with disabilities can be contributed to the role expectations of both mothers and fathers with regard to their childcare responsibilities. This is so as research suggests, fathers typically hold less responsibility for the direct care services required by their child, whereas mothers are expected to provide for their child's care demands regardless of what their family may need or require. To further explain, Bristol et al. (1988) reported fathers are typically expected to provide financially for their family whereas mothers are typically expected to assume more of the care demands for their disabled child. As a result, Little (2002) found that fathers tend to report decreased stress levels involving the care demands of their disabled child versus the mothers who report increased stress levels due to their child's care demands. In part, this has to do with fathers seeking employment and work away from the pressures of home life, resulting in reduced overall parenting stress when compared to mothers of these same disabled children (Vetere, 1994).

Other studies suggested mothers of disabled children for the most part have assumed majority of the child care demands and responsibilities thus, fathers tend to focus on other home life responsibilities, to include securing their financial stability (e.g. Floyd & Gallagher, 1997; Gray & Holden, 1992; Vetere, 1994). Which is why, most research is dedicated to the burdens of childcare of disabled children associated with mothers and maternal stress versus that of the fathers. Vetere (1994) reported the physical and emotional exhaustion of mothers often times occurs due to their childcare responsibilities, thus, they tend to emotionally and physically neglect themselves.

Therefore, as reported by Gray and Holden (1992) these mothers tend to be overwhelmed with exhaustion and are limited with receiving respite as compared to their husbands.

This is so as mothers with disabled children tend to give up their employment and other sources of social support as they dedicate their time and energy to the demands of their home to include the behavioral demands of their disabled child (Gray & Holden, 1992).

However, over the years researchers have argued that mothers tend to "chose" this life style, as now-a-days there is an egalitarian division of domestic and childcare responsibilities (Brannen & Moss, 1991; Deutsch, 1999; Goldberg, 2013; Hochschild, 2012). However, despite this argument, limited research exists with regard to how responsibilities might be measured or how one might determine what an equal distribution of childcare responsibilities really signifies.

Gornick and Meyers (2009) for example, argued for the importance of gender equality in parenthood and employment however; failed to describe what equality of gender roles really means and what an actual fair distribution of house work and childcare responsibilities across gender is. Other critics in this area, like Orloff (2009) and Sullivan (2013) reported research in gender equality in parental work and responsibilities to be quite scarce as that means "equality with one's partner might take precedence over other family goals of attending to vulnerabilities of the cared-for (see Fineman, 2009), and as a result, researchers who study these matters will not know what equality in parental responsibilities looks like and how to even begin to measure it.

### **Summary**

Fragile X Syndrome was commonly known as the cause of Mental Retardation in individuals as it is caused by a mutation in the Fragile X Mental Retardartion-1 gene that hinders the development and production of the Fragile X Mental Retardation Protein (Hagerman, 2006). However, since FXS does not possess the common characteristics of Mental Retardation, it was later considered to be a diagnosis under the Autism Spectrum Disorder. This is so, as approximately 4-8% of Autism diagnoses were traced back to FXS, thus, FXS was studied as a genetic disorder especially since it has similar features of all etiological subtypes of autism (Abrahams & Geschwing, 2010; Hagerman, 2008; Hagerman, Narcisa & Hagerman, 2011). However, up until recently, FXS has been recognized as having its own set of diagnostic criteria, and because of such, studies have shown there are significant differences in Autism related cases in comparison to that of FXS cases. For instance, FXS includes but is not limited to the following symptoms: gaze avoidance, lack of attention, social communication impairment, social anxiety and impairment in executive functioning (Abrahams & Geschwing, 2010; Cohen et al., 1995; Kaufmann et al., 2004). Other studies have found significant differences in profiles of Autism as compared to FXS profiles as measured by assessments and other psychological tools (Cohen et al., 2005; Dissanayake et al., 2009). Which is why, examining parental stress across gender among parents of children with FXS is significant as most research is dedicated to parental stress of parents of children with Mental Retardation and Autism.

Moreover, considering FXS has recently been recognized as having its own diagnostic criteria it is noteworthy to consider discussing the effects of parental stress and

marital satisfaction due to the high demands of childcare responsibilities. To further explain, a child diagnosed with FXS is considered to have extremely cognitive, emotional and behavioral problems, thus, effective treatment planning, support systems and appropriate childcare strategies should be researched, in order to help reduce couple dyads stress, which could possibly result in marital dissatisfaction among parents of children with FXS.

Furthermore, parental stress among parents with children with FXS is highly related to the child's inabilities to independently function across several domains, such as intellectually, developmentally, emotionally and physically. There are also other major impairments observed in a child with FXS such as the inability to socialize with others and build reciprocal relationships. Children with FXS also tend to display problematic overt behaviors and respond incongruently (emotionally) to situational demands, which are among some of the most common stressors of parents. These however, are only few of the stressors parents of children with FXS face, as the challenges begin as soon as they learn about their child's diagnosis which lasts their whole life time as their caregiver role and childcare responsibilities never seem to cease. Additionally, the financial responsibility associated with raising a child with FXS may be significantly higher than that of raising a typically developing child due to the high demands of the child's needs to include medical and intervention services and expenses.

Parents of children with FXS and other intellectual and pervasive developmental disorders tend to experience increased levels of stress as compared to parents of typically developing children (e.g. Britner et al., 2003; Dumas et al., 1991; Johnson et al., 2003;

Reyns, 2006; Rodriquez & Murphy, 1997; Sander & Morgan, 1997). A number of studies have suggested parental stress of disabled children are attributed to the external and overt problematic behaviors displayed by these children. Research in this area also suggested, parents tend to experience elevated stress levels due to the inability of their child to emotionally connect with them, resulting in little emotional fulfillment for the parent. Other studies have demonstrated parents' increased levels of stress resulting from their child's specific characteristics, demands and care needs (Dutra, 1999; Floyd & Gallagher, 1997, Hawley et al., 2003; Little, 2002; McKinney & Peterson, 1987; Schopler & Mesiboy, 1992; Vetere, 1994).

However, regardless of the source of parental stress among parents of children with disabilities, research has reported parenting stress affects many areas among and within the family systems. It is believed parents of children with elevated stress levels tend to experience emotional and psychological problems, like anxiety and depression (Baker et al., 2003). Parents also tend to experience negative parenting experiences/behaviors due to their elevated stress levels that ultimately have a spillover effect onto their child, spouse and other family members (Dumas & Wekerie, 1995; Hodapp et al. 2003; Johnson et al., 2003; Kasari & Sigman, 1997; Morris, 2000; Reyns, 2006; Walker, 2000). Reyns (2006) further suggested the severity of the spillover effect is highly linked with the parent's increased level of stress due to the actual impairment and behaviors of the disabled child.

Stores et al. (1998) discussed the different sources of stress experienced across gender, as he suggested parental gender is highly associated with the different sources of

stress experienced by both mothers and fathers. It was argued maternal roles and their increased levels of stress are associated with childcare responsibilities whereas paternal stress is associated more with house work and the financial burden of maintaining a household (Baker & Heller, 1996; Dumas & Wekerie, 1995; Stores et al., 1998; Webster-Stratton, 1990). However, regardless of the stressor and its differences, research suggests mothers tend to experience increased levels of stress as compared to fathers of children with developmental disorders (Baker & Heller, 1996; Harris, 1984; Leslie et al., 1991; Goldberg, 2013). Overall, there is no doubt parental stress is significantly elevated due to the child's developmental disorder as specified by the demands of their childcare responsibilities than parents of typically developing children.

Lastly, marital satisfaction may be altered due to the increased levels of parental stress resulting from raising a child with an intellectual or pervasive developmental disorder. When this occurs, marital dissatisfaction may occur since the dyad's marital cohesiveness and unity is altered. Other studies have further suggested marital unity provides stability, security and a source of foundation for the family thus, when this is disturbed or changed due to a life changing event, like that of raising a disabled child, parental stress may increase resulting in marital dissatisfaction. (Reyns, 2006; Rodrigue et al., 1990; Shakhmalian, 2005). This is also in association with the limited amount of time parents have to nurture and maintain their marital relationship due to their shared childcare responsibilities with regard to their disabled child.

Children with pervasive developmental disorders like FXS tend to place greater care demands on their parents than typically developing children; thus, parents tend to

neglect their marital relationship, resulting in marital dissatisfaction (Fisman & Wolf, 1991; Mullen, 1997; Reyns, 2006). As a final note, no matter the source of the stressor, the child's diagnosis or care needs, the research available suggested parental stress among parents of children with developmental disorders tends to result in decreased levels of marital satisfaction. However, because none of the aforementioned studies have specifically investigated if parents of children with FXS are affected by the high demands of their childcare responsibilities that may or may not result in marital dissatisfaction, the intention of this study is to do so.

### Chapter 3: Research Method

#### Introduction

Numerous researchers have explored and examined how parents of children with developmental disabilities experience higher levels of stress in comparison to parents of typically developing children (e.g., Byrne, 2014; Chapman, 2013; Hauser-Cram, Warfield, Shonkoff & Kauss, 2001). However, despite the immense amount of research with regard to this problem, there is limited research on how stress differs between the mothers and fathers of children with such developmental disabilities, in particular among parents of children with FXS. Therefore, this quantitative experimental research study was conducted to examine the amount of childcare responsibility as the stress variable that parents of children with FXS experience. Moreover, this research study was conducted to help determine whether there is a relationship between the independent variables, parental stress and the amount of childcare responsibilities, and the dependent variable, marital satisfaction. I also explored if the stressor of childcare responsibility affects or influences parents' marital satisfaction while controlling for the covariates of parental age, socioeconomic status, parents' level of education, race/ethnicity, and number of years married.

In this chapter, I discuss the following: a detailed description of the research design to include but not limited to the method used to collect the data, instrumentation, sample, and data analysis. This chapter also includes an overview of why this particular research design was selected and more specifically I discuss in detail the data collection process to include the population and sample size, which was based on a power analysis

using the GPower computer program/software. Lastly, the protection of human participants and ethical considerations within this study are reviewed and discussed in detail.

## **Research Questions and Hypotheses**

RQ1: How does the perceived level of stress around shared childcare responsibilities of mothers and fathers of children with FXS differ?

 $H1_0$ : There are no statistically significant mean differences between mothers' and fathers' parenting stress levels due to their shared childcare responsibilities, as measured by the shared childcare responsibilities scale.

 $H1_a$ : There are statistically significant mean differences between mothers' and fathers' parenting stress levels due to their shared childcare responsibilities, as measured by the shared childcare responsibilities scale.

RQ2: What is the relationship between the level of stress of parents of children with FXS and the amount of shared childcare responsibilities and marital satisfaction?

 $H2_0$ : The level of stress of parents of children with FXS will not significantly predict marital satisfaction, as measured by the level of marital satisfaction.

 $H2_a$ : The level of stress of parents of children with FXS will significantly predict marital satisfaction, as measured by the level of marital satisfaction.

H3<sub>0</sub>: The amount of shared childcare responsibilities of parents of children with FXS will not significantly predict marital satisfaction, as measured by the level of marital satisfaction.

H3<sub>a</sub>: The amount of shared childcare responsibilities of parents of children with FXS will significantly predict marital satisfaction, as measured by the level of marital satisfaction.

## **Research Design and Rationale**

The research methodology design most appropriate for this research study is that of a quantitative research design using a multiple linear regression and independent sample *t*-test statistical analysis. The statistical analysis designed for this study includes having and using a demographic survey, the Kansas Marital Satisfaction scale instrument, to measure marital satisfaction (Schumm et al., 1983), and the Sharing of Childcare Responsibilities scale and Parental Stress Level scale to measure the parent's level of stress (Ki & Joanne, 2014) and the amount of childcare responsibilities (Goff et al., 1990). This study was not only conducted to determine if a relationship exists between the independent variables, parental stress and the amount of childcare responsibilities, and the dependent variable, marital satisfaction, but was also conducted to examine any gender differences affecting the parent's marital satisfaction as a result their stress levels due to the amount of shared childcare responsibilities.

The independent variables of parental stress and the amount of childcare responsibilities were measured taking into consideration certain qualifying criteria for each participant. For instance, the participants needed to have a child between the ages of 2 and 12 who has been diagnosed with FXS by a medical doctor, physician, psychiatrist, psychologist, or other mental health professional and be legally married, and the child diagnosed with FXS needs to be living with them for at least 6 months. It is

also significant to point out that I did not influence or control the environment of the participants in any way or form as the purpose of this study was to demonstrate (if any) a statistically significant relationship between the variables.

Preliminary recruitment of participants was done at the Fragile X Syndrome Alliance of Texas located in the southwest region of Texas, specifically in San Antonio, Texas. Information for this study was also publicized using flyers, notices, and handouts that were randomly given and provided to families present at the Fragile X Syndrome Alliance of Texas Awareness meetings, at support groups held every month, and at their annual walk, which was held in San Antonio, Texas. Additionally, the parents of children with FXS who volunteered to participate in the study were directed through those flyers, notices, and handouts to a certain website created only for the completion of the surveys required. The website created included a demographic questionnaire, the Kansas Marital Satisfaction scale and the Sharing of Childcare Responsibilities scale, and Parental Stress Level scale. The participants, upon logging on into the website, were briefed about the study and were presented with a confidentiality form and a consent form, which was an initial requirement for them to read and acknowledge before they could activate and begin the surveys.

### Methodology

# **Population**

The participants selected for this study needed to be parents of at least one child diagnosed with FXS between the ages of 2 and 12. These participants also needed to be legally married, and their child who is diagnosed with FXS should have been living with

them for at least 6 months. In addition, these participants learned about this research study by attending their monthly awareness meetings, support group meetings, or through their annual walk by form of a flyer, notice, or handout. Additionally, postings about the study were included and added to various websites, such as in social media platforms, online parental support groups, and FXS specific diagnosis online forums. The information in the flyers also had information about the study, such as my contact information and its benefits. In addition, even though information about the surveys and about the research study was provided via the flyers, notices, and handouts, it was also provided via an informed consent form in the website. Lastly, because the surveys were anonymous in nature, the participants were asked to confirm they met all of the eligibility requirements before completing the surveys, which was solely based on their integrity and honesty.

## **Power Analysis for Target Sample Size**

A power analysis was conducted, and the predictor and criterion variables were included in this statistical analyses using a linear regression model in order to effectively test the hypotheses. The two predictor variables were the childcare responsibilities and parental stress levels, and the criterion variable was marital satisfaction. To calculate an empirically valid sample size for the regression, the G\*Power tool 3.0.10 was used. With a medium effect size,  $\int_{1}^{2} = 0.15$ , power set at 0.80, and p < 0.05 (Howell, 2010), and with having two predictor variables of level of stress of parents and childcare responsibilities (IV), one criterion variable measuring marital satisfaction (DV), and the five covariates of parental age, socioeconomic status, parent's level of education,

race/ethnicity, and number of years married, the required sample size was determined to be N = 100.

## **Sampling Procedure**

Having a representation of the population of interest was used to help minimize potential sampling bias such as making statistical inferences or generalizations from the sample of the population (Frankfort-Nachmias & Nachmias, 2008). In addition, considering this study was conducted to examine parental stress and the amount of childcare responsibilities among parents, a stratified random sample was necessary as both female and male parents who met the selection criteria were recruited. Since I identified gender differences of parental stress and marital satisfaction due to the sharing of childcare responsibilities, this type of sampling strategy was appropriate to use for this particular study. More so, with this type of sampling strategy, there is an equal chance of selecting each unit within a particular group of the population when creating the sample (Lund Research, 2012).

With all the above criteria, other sampling strategies would not have been appropriate, as the use of stratified sampling most benefits this study because it involved obtaining a population sample that required the population to be divided into smaller groups, which in this case were the mothers and fathers of children diagnosed with FXS. For example, a convenience sample would not have been appropriate to use in this study, as it involves selecting a certain number of participants from a unit or total number within a given population (Lund Research, 2012).

Additionally, using a stratified sample is a rather quick, effortless, and

inexpensive technique as compared to other probability sampling strategies (e.g., systematic random sampling and cluster random sampling), as stratified sampling simply involves selecting participants who are most easily accessed. However, this type of strategy could be red flagged for many biases to include but not limited to an under or over representation of a particular population, not being representative of the population, and this type of sample is inevitably not being chosen at random, which could also affect making generalizations about the population at hand (Frankfort-Nachmias & Nachmias, 2008).

#### **Recruitment Procedure**

The recruitment of parents of children diagnosed with FXS was through the use of flyers, notices, and handouts that were handed to them during their monthly awareness meetings, support group meetings, and at their annual awareness walks in local community areas around San Antonio, Texas. The interested parents who met the study parameters mentioned above (e.g., parents needing to be legally married and needing to have a child who is diagnosed with FXS) were then directed through these means of communication to log on to a website by inserting the appropriate web address as found in the flyers, handouts, and notices. This website was created solely for the purpose of completion of the necessary surveys, and these parents only had access to them if they met the required criteria to participate in the study, which was solely based on their integrity.

This type of recruitment of parents follows the ethical guidelines for research with human subjects. It is also significant to highlight that before the parents began the

surveys, they were first asked to complete a demographic information page, in which identifying information was excluded, like their name, phone number, and address. Furthermore, before they could continue on with the surveys, they were asked to give an informal consent as described and found in the website so that they were able to proceed with the surveys. The participants, upon giving their informed consent, could then take the survey; however, they could also choose to drop out of the study at any given time. The creators of the website do not know who completed the surveys, as there is no identifying information provided; thus, they are not able to match the consent agreement forms to the surveys. I was also unaware of the identity of the participants, as all participants who took part in this study were kept anonymous.

Once the surveys were completed, all the data were then downloaded, and a spreadsheet data file containing all of the pertinent information was created and secured. The data file was password protected, and I was the only one who had the password to access the spreadsheets. Upon review of the data collected, all incomplete entries were then discarded, and the rest of the data were analyzed using SPSS 21.0.

### **Instrumentation and Operationalization of Constructs**

#### **Parent's Stress Level Scale**

The independent variables in this study are the level of stress of mothers and fathers and the amount of childcare responsibilities, and the covariates are parental age, socioeconomic status, parent's level of education, and number of years married. The level of stress of mothers and fathers and the amount of childcare responsibilities were measured using the Sharing of Childcare Responsibilities scale and Parental Stress Level

scale that have been used in similar research by Baxter et al. (2000) and Ki and Joanne (2014).

This scale, specifically looking at parent's stress levels, was designed to evaluate the overall score of parent's stress level on a 7-point Likert scale ranging from 1: *do not feel any pressure or stress* to 7: *feel a lot of pressure and stress* (Baxter et al., 2000). The seven sources of stress that were evaluated were the following: (a) accompanying the child to training in any one type of early intervention class or training center, (b) domestic training with the child, (c) allocating time between child care and work or housework, (d) guiding the child to learn, (e) handling the emotions and behaviors of the child, (f) the differences between the development of their child and that of other children of the same age, and (g) other people's view of their child care (Baxter et al., 2000).

The Cronbach's alpha for this scale is 0.90, indicating high internal reliability and considering it measures what it is supposed to measure, it has also has good validity (Baxter et al., 2000; Ki & Joanne, 2014). In addition, this instrument, as indicated in previous studies (e.g., Baxter et al., 2000; Fowers, 1991; Ki & Joanne, 2014) is a valid and reliable instrument; however, its psychometric properties were also tested in this study.

### **Shared Childcare Responsibilities Scale**

The other independent variable, childcare responsibilities, was measured using the Sharing of Childcare Responsibilities scale and Parental Stress Level scale, which have been used in similar research (Goff et al., 1990). The participants were asked to assess their spouse's amount of shared childcare responsibilities when using this scale, as

it was used in Goff's et al. (1990) research.

This scale consists of a single item measured on a 7-point Likert scale ranging from 1: *no responsibility* to 7: *a lot of responsibility*. This item asks the parents to indicate the extent to which their spouse takes on the responsibility for helping their child (Goff et al., 1990). Furthermore, as suggested by Goff et al. (1990), this scale used appropriate anchors that indicated varying degrees of shared childcare responsibility that were included for responses 2 through 6. The reliability of this response is assumed to be 1.00.

With this being said, it is possible that correlating the responses of spouses could provide an estimate of the reliability of single items such as this one, however, because this questionnaire is to be completed anonymously, this scale can't be matched as needed for this analysis. Therefore, as Goff et al (1990) determined in their study, the same determination will also be true for this study, that the assumed value of 1.00 is a conservative approach because any corrections for attenuation on this variable would have no effect on the estimated true score correlation.

#### **Kansas Marital Satisfaction Scale**

The dependent variable of marital satisfaction will also be used to assess the level of marital satisfaction of spouses as used in previous research (Fowers, 1991). For the purpose of measuring this variable, the Kansas Marital Satisfaction Scale (KMSS) will be administered.

The Cronbach's alpha for this scale ranges from .84 -.98. Discriminate validity of the KMSS was tested by correlating it with the Dyadic Adjustment Scale. The items used

for the correlation were from the satisfaction subscale and ranged from a high of .76 (p<.001) to a low of .39 (p<.04) (Crane, Middleton, & Bean, 2000 as cited by Botello, 2014). Correlations between the KMSS and five subscales from the Family Environment Scale provided construct validity (Botello, 2014). These are cohesion .42, control .08, morale/religious orientation .31; active/recreational orientation .11; and independents .19 (Crane et al, 2000). The KMSS has also been correlated with marital social desirability (.42 to .54, positive regard (.42 to .70), individual social desirability (.05 to .39), locus of control (.18 to .31), church attendance (.22 to .24), total family income (.30), and personal depression (.33) (Crane et al, 2000 as cited by Botello, 2014).

The KMSS is an instrument that is designed to measure marital satisfaction using only three items (Schumm, Nichols, Schectman & Grigsby, 1983). The three items are as follow: 1) How satisfied are you with your husband (or wife) as a spouse 2) How satisfied are you with your marriage and 3) How satisfied are you with your relationship with your husband (or wife)? This scale also utilizes a seven point Likert scale: 1 - Extremely Dissatisfied, 2 - Very Dissatisfied, 3 - Somewhat Dissatisfied, 4 - Mixed, 5 - Somewhat Satisfied, 6 - Very Satisfied and 7 - Extremely Satisfied (Schumm et al., 1983). Additionally, the mean of the scores of this scale was used to measure marital satisfaction among parents of children with FXS.

The KMSS underwent numerous studies throughout the state of Kansas and these studies reported this scale to have high reliability and validity. Additionally, this instrument's coefficients were evaluated in which greater than .9 is excellent, .8 or more is good, .7 or more is acceptable, .6 or more is questionable, greater than .5 is poor and

less than .5 is unacceptable (George & Mallery, 2010 as cited in Botello, 2015). Also, as described by Botello (2014), the discriminate validity of the KMSS was tested by correlating it with the Dyadic Adjustment Scale. The items used for the correlation were from the satisfaction subscale and ranged from a high of .76 (Schumm et al., 1983), however its psychometric properties will also be tested in this study.

### **Covariates**

The covariates are (a) parental age, (b) socioeconomic status, (c) parent's level of education (d) race/ethnicity and (e) number of years married. Parental age was measured using this question, "What year were you born?" and their age was calculated from the birth date that was provided. Skoog and Ciecka (2010) specified participants are more likely to provide their birthdate versus their actual age. The family's socioeconomic status was measured using the following question, "What is your family's approximate yearly income?" As indicated by Caro and Cortes (2012) this type of question for the most part is coded from 1 = Less than \$25,000 to 12 = More than \$150,000.Caro andCortes (2012) have used this single item question in many of their national demographic questionnaires. Parent's level of education, a categorical variable will be measured using this question, "What is the highest degree or level of school you have completed? The responses will be coded as 1 = No schooling completed, 2 = Some high school, no diploma, 3 = High school graduate with diploma or the equivalent (for example: GED), 4 = Some college credit, or vocational training, 5 = Associate degree, 6 = Bachelor's degree, 7 = Master's degree, 8 = Professional degree, and 9 = Doctorate degree. The number of years married was asked using this question: "How many years

have you been married?" Race and ethnicity were also asked using this question, "What is your race/ethnicity? Lastly, the parent's gender was measured via a categorically coded question, "What is your gender?" with coding being 1 = female and 0 = male.

## **Data Collection and Analysis**

In order to conduct this research study, an official approval was first obtained from the Institutional Review Board (IRB) at Walden University. Walden University's approval number for this study is 10-18-16-0438630; it expires on October 17, 2017. Once the approval was obtained, the participants for this study were provided with the web address for completion of the surveys through receipt of a flyer, notice, or handout. The website created for the purpose of completion of the surveys was necessary in order to collect all the necessary data pertaining to this study. This website was secured and the anonymity of each participant was ensured.

When the participants first logged into this website, the first page presented was the consent form. Even though this was not a formal consent form, in which a signature was required, the participants were asked to agree to the nature of the study by providing their consent by checking off a box with a "I agree" in order to proceed to the surveys. However, if they checked off the "I do not agree" box, they were not allowed to access the survey instruments and that terminated their participation in this study. Conversely, if they did agree and gave consent, a second page followed. This page provided the participant with a confidentiality statement. Thereafter, a third page followed, and this page provided the participant with general information about the research study. The

participants were then given ample time to review the information provided in the confidentiality statement and in the general information page, and if need be, they were able to go back and forth to such pages. Once the participant decided to proceed forward, they were directed to the surveys created on Survey Gizmo (www.surveygizmo.com), through the website that was created (www.fxsparents.com) for the sole purpose of this study. If, for whatever reason, the participant decided not to complete the surveys, they could do so without any repercussion. If they completed the surveys, the participant was again provided with general information about the study, and my contact information was offered on the last page of the website once the survey was completed. Once this final page was presented, the participants were thanked for their time and no further participation on their behalf was necessary.

Once all of the necessary data were collected, the datum was then screened for any missing data, accuracy of the date file, normality of the distribution, including both skewness and kurtosis, and outliers, which were all analyzed using SPSS 21.0. The sample's data were explained using descriptive statistics, like male or female. In addition, frequencies and percentages for categorical variables were presented, interpreted, and reported (e.g., gender). The standard deviation, mean, and minimum and maximum scores for the covariates, like parental age, parent's level of education. and number of years married were also be interpreted and reported. However, before beginning the data analysis, all incomplete surveys were discarded and excluded from the analysis, as suggested by Muijs (2010).

The scale data that were obtained for this study were from the following scales: the Sharing of Childcare Responsibilities scale, the Parental Stress Level scale and the Kansas Marital Satisfaction scale. However, prior to analyzing the data from these Scales, a Cronbach's alpha ( $\alpha$ )—which is an indicator of a scale's interitem reliability—was computed for each subscale (Bellows, 2014). A Cronbach's  $\alpha >= .70$  is considered adequate to good, and a Cronbach's  $\alpha >= .50$  is the minimum acceptance level (Cohen & Cohen, 1983).

Additionally, recommended statistical procedures were incorporated to test for any violations of statistical assumptions for scale data used within the regression model. For instance, Rosenthal and Rosnow (2008) described skewness and kurtosis values be computed and Kolmogorov-Smirnov tests be calculated in order to determine whether the scores of the test variables and testing subscales are normally distributed. Thereafter, if nonnormality is evident, the variables should be transformed in accordance with the recommended procedures (Muijs, 2010).

To determine multicollinearity between the independent and dependent variables a variance inflation factor (VIF) was computed in order to measure the degree of correlation between the beta coefficients (Rosenthal & Rosnow, 2008). If the VIF value is significant (5.00 or higher), multicollinearity will be evident. However, multicollinearity may be reduced if the VIF value is significant for both the predictor and criterion variables which are standardized (e.g., mean of 0 and standard deviation of 1). These variables are then used in the statistical analysis in alignment with the appropriate

recommendations for mediation analyses (MacKinnon, Lockwood, Hoffman, West, & Sheets, 2002, as cited by Bellow, 2014).

## **Descriptive Statistics**

The use of descriptive statistics was necessary in order to calculate and graph accordingly the data collected and analyzed from the following subscales: The Kanas Marital Satisfaction scale, the Sharing of Childcare Responsibilities scale, and the Parental Stress Level scale. This is in an effort to present the data collected with regard to marital satisfaction, parent's stress levels, and their experiences with their shared childcare responsibilities. The descriptive statistics also included information about the standard deviation, number of participants, the mean and percentages.

## **Inferential Statistics to Test Hypotheses and Answer Research Questions**

To answer research question number one: How does the perceived level of stress around shared childcare responsibilities of mothers and fathers of children with FXS differ, an independent samples *t*-test was used in order to understand the differences of the perceived level of stress of mothers and fathers as accounted for by the scores from The Sharing of Childcare Responsibilities Scale and Parental Stress Level Scale. In addition, a multiple linear regression analysis was used to investigate and examine the functional relationship between the two independent and dependent variables. This is in efforts to answer research question number two: What is the relationship between the level of stress of parents (IV) of children with FXS and the amount of shared childcare responsibilities (IV) and marital satisfaction (DV)?

## Threats to Validity

There are also possible external and internal threats of validity that could potentially jeopardize the validity and reliability of this study. For this reason, all limitations, implications, generalizations and assumptions were thoroughly considered and addressed. Prior to encountering this probability, a strategic plan was developed in order to properly assimilate these threats (Frankfort-Nachmias & Nachmias, 2008).

Moreover, prior to conducting the regression, the assumptions of linearity, homoscedasticity and multicollinearity were determined. These assumptions were assessed using SPSS 21.0 by running and creating scatterplots and by examining the VIF and its values. Linearity and homoscedasticity were examined with scatterplots and the absence of multicollinearity will be met if the VIF values is less than 10 (Stevens, 2009).

#### **Ethical Considerations**

This study was conducted in accordance with all ethical guidelines pertaining to research involving human participants. This study was also performed in accordance with Walden University requirements, expectations and procedures. Additionally, before conducting any data collection processes, permission to do so was first obtained by Walden University's IRB. The participants were also informed about the nature of the study, and were provided with the researcher's contact information via an informed consent form. The consent form provided included information about the study, purpose of the research and confidentiality information. All participants volunteered to take the surveys and remained anonymous throughout the study. The participants also had the right to discontinue their participation in the study at any given time without any

ramification. Lastly, all data received was safely secured and stored in a password protected database which could only be accessed by the researcher for a minimum of 5 years, and thereafter it will be properly discarded.

## **Summary**

The purpose of this chapter was to provide a detailed overview of this research's design and methodology. The chapter includes information about the independent and dependent variables, research questions, hypothesis, specific targeted population, sample size and method. In addition, a description about participation recruitment is included and specifics about the different instruments that were used to collect the data was also provided. The data analysis plan, all ethical procedures to include but not limited to confidentiality, informed consent and study's procedures and strategies was included as well. This chapter is concluded with a summary section and an introduction to chapter four is presented.

Chapter four follows the conclusion of this chapter and it includes and discusses the findings of the study which is collected from all of the surveys conducted online. The data collected answered the following questions: how does the perceived level of stress around shared childcare responsibilities of mothers and fathers of children with FXS differ and what is the relationship between the level of stress of parents of children with FXS and the amount of shared childcare responsibilities and marital satisfaction?

## Chapter 4: Results

#### Introduction

The purpose of this quantitative research study was to examine more in depth the level of stress parents (across gender) of children diagnosed with FXS experience due to the amount of their childcare responsibility. I also investigated the relationship between the level of stress of parents of children with FXS and the amount of shared childcare responsibilities and marital satisfaction. In short, the intention of this quantitative research study was to examine and compare parental stress as it relates to the amount of childcare responsibilities and marital satisfaction of parents of children with FXS.

The intention of this research study is to also enhance the body of knowledge in this area and further the understanding of mental health professionals, clinicians, psychologists, and the like about the differences of gender stress as it relates to their shared childcare responsibilities and marital satisfaction. In this chapter, I describe the type of research method analyses used for this study. I also discuss the summary of results from the statistical analyses used, and the descriptive statistics and frequencies for all categorical and ordinal variables are provided.

According to the problem statement and purpose of the study, I addressed the following research questions:

RQ1: How does the perceived level of stress around shared childcare responsibilities of mothers and fathers of children with FXS differ?

 $H1_0$ : There are no statistically significant mean differences between mothers' and fathers' parenting stress levels due to their shared childcare responsibilities, as measured by the shared childcare responsibilities scale.

 $H1_a$ : There are statistically significant mean differences between mothers' and fathers' parenting stress levels due to their shared childcare responsibilities, as measured by the shared childcare responsibilities scale.

RQ2: What is the relationship between the level of stress of parents of children with FXS and the amount of shared childcare responsibilities and marital satisfaction?

 $H2_0$ : The level of stress of parents of children with FXS will not significantly predict marital satisfaction, as measured by the level of marital satisfaction.

 $H2_a$ : The level of stress of parents of children with FXS will significantly predict marital satisfaction, as measured by the level of marital satisfaction.

H30: The amount of shared childcare responsibilities of parents of children with FXS will not significantly predict marital satisfaction, as measured by the level of marital satisfaction.

H3a: The amount of shared childcare responsibilities of parents of children with FXS will significantly predict marital satisfaction, as measured by the level of marital satisfaction.

In this chapter, as described above, I reevaluate the data collection procedure, examine the data collected for the study, including distributions and normality assumptions, and describe the statistical significance proposed within the methodology section of this chapter.

#### **Data Collection**

In order to conduct this research study, an official approval was first obtained from the IRB at Walden University (Approval Number: 10-18-16-0438630). Once the approval was obtained, the participants for this study were provided with the web address for completion of the surveys through receipt of a flyer, notice, or handout. The website created for the purpose of completion of the surveys was necessary in order to collect all the required data pertaining to this study. This website was secured, and the anonymity of each participant was ensured.

When the participants first logged into the website, the first page presented was the consent form. Even though this was not a formal consent form, in which a signature was required, the participants still had to agree to the nature of the study by providing their consent by checking off a box with an "I agree" in order to proceed onto the surveys. However, if they checked off the "I do not agree" box, they were not allowed to access the survey instruments, and at that point, their participation in this study was terminated. Conversely, if they did agree and gave consent, a second page followed. This page provided the participant with a confidentiality statement. Thereafter, a third page followed, and this page provided the participant with general information about the research study. The participants were given ample time to review the information provided in the confidentiality statement and in the general information page, and they were able to go back and forth to a page if needed. Once the participants decided to proceed forward, they were directed to the surveys created on Survey Gizmo (www.surveygizmo.com) through the website created (www.fxsparents.com). If, for

whatever reason, the participants decided not to complete the surveys, they were able to do so without any repercussion. However, if they completed the surveys, the participants would once again be provided with my contact information and general information about the study at the end of the survey. Once this final page was presented, the participants were then thanked for their time, and no further participation on their behalf was necessary.

Data were collected from October 19, 2016 through October 31, 2016 in which 132 surveys were collected. However, of the 132 surveyed participants, 128 were eligible to participate per the participant invite requirements, indicating they were legally married, had a child diagnosed with FXS between the ages of 2 and 12, and that their child had lived with them for the past 6 months. Once the data from these 128 surveys were collected, they were once again screened for missing data, normality of the distribution, to include both skewness and kurtosis, and outliers that were all analyzed using SPSS 21.0.

The sample's data were explained using descriptive statistics, like male or female. In addition, frequencies and percentages for categorical variables were presented, interpreted, and reported (e.g., gender). The standard deviation, mean, and minimum and maximum scores for continuous variables, like parental age, parent's level of education, and number of years married were also interpreted and reported. However, before beginning the data analysis as indicated above, any ineligible or incomplete surveys were discarded and excluded from the analysis, as suggested by Muijs (2010).

The scale data obtained for this study are from the following scales: the Sharing

of Childcare Responsibilities scale, the Parental Stress Level scale, and the Kansas Marital Satisfaction scale. However, prior to analyzing the data from these scales, a Cronbach's alpha ( $\alpha$ )—which is an indicator of a scale's interitem reliability—was computed for each of the subscale. A Cronbach's  $\alpha > = .70$  is considered adequate to good, and a Cronbach's  $\alpha > = .50$  is the minimum acceptance level (Cohen & Cohen, 1983).

Additionally, recommended statistical procedures were incorporated to test for any violations of statistical assumptions for scale data used within the *t* test and the regression model. For instance, Rosenthal and Rosnow (2008) described skewness and kurtosis values be computed and Kolmogorov-Smirnov tests be calculated in order to determine whether the scores of the test variables and testing subscales are normally distributed. Thereafter, if nonnormality was evident, the variables should be transformed in accordance with the recommended procedures; however, the noncontinuous variables in this study were all normally distributed, and therefore, no transformation was needed (Muijs, 2010).

To determine multicollinearity between the independent variables, a VIF was also computed in order to measure the degree of correlation between the beta coefficients (Rosenthal & Rosnow, 2008). If the VIF value was significant (5.00 or higher), multicollinearity would be evident. However, multicollinearity was not a concern for the layout of this particular study since there was only one predictor variable in the regression model. By definition of collinearity diagnostics, multicollinearity is only a

concern when there is more than one independent (predictor) variable in the regression model (MacKinnon et al., 2002 as cited by Bellow, 2014).

## Results

# **Participant Demographics**

In this research project, there were 128 participants. Of these, 126 (98.4%) were from the United States, and two (1.6) were from outside of the United States (Table 1). Of the 128 participants, 83 (63.7%) were females and 45 (36.3%) were males (Table 2). Table 1

Country Distribution of Participants

|       |                      | Frequency | Percent | Valid percent |  |
|-------|----------------------|-----------|---------|---------------|--|
| Valid | Australia            | 1         | .8      | .8            |  |
|       | Canada               | 1         | .8      | .8            |  |
|       | <b>United States</b> | 126       | 98.4    | 98.4          |  |
|       | Total                | 128       | 100.0   | 100.0         |  |
|       |                      |           |         |               |  |

Table 2

Gender Distribution of Participants

|       |        | Frequency | Percent | Valid percent |  |
|-------|--------|-----------|---------|---------------|--|
| Valid | Female | 83        | 63.7    | 63.7          |  |
|       | Male   | 45        | 36.3    | 36.3          |  |
|       | Total  | 128       | 100.0   | 100.0         |  |
|       |        |           |         |               |  |

In terms of the educational background of the participants, Table 3 provides a breakdown of number and percentage of participants in each education level category. The most frequent degree earned by the parents was Bachelor's, 43 (34.7%). Only one (.8%) did not receive high school diploma.

Table 3

Education Background of Participants

|       |  | Frequency | Percent | Valid percent |
|-------|--|-----------|---------|---------------|
| Valid | Associates degree                      | 18        | 14.5    | 14.5          |
|       | Bachelor's degree                      | 43        | 34.7    | 34.7          |
|       | Doctoral degree                        | 5         | 4.0     | 4.0           |
|       | GED                                    | 2         | 1.6     | 1.6           |
|       | High school graduate                   | 4         | 3.2     | 3.2           |
|       | Master's degree                        | 24        | 16.1    | 16.1          |
|       | Professional certificate               | 22        | 17.7    | 17.7          |
|       | Some college                           | 6         | 4.8     | 4.8           |
|       | Some high school completed, no diploma | 1         | .8      | .8            |
|       | Trade school                           | 3         | 2.4     | 2.4           |
|       | Total                                  | 128       | 100.0   | 100.0         |
|       |  |           |         |               |

There were 11 (8.9%) participants who identified themselves as American Indian or Alaskan Native, two (1.6%) were Asian, eight (6.5%) were Black or African

American, 24 (19.4%) identified as Hispanic, and 83 (63.7%) were White (Table 4).

Table 4

Racial Background of Participants

|   | Frequency | Percent | Valid percent |
|---|-----------|---------|---------------|
| Valid American Indian<br>or Alaska native | 11        | 8.9     | 8.9           |
| Asian                                     | 2         | 1.6     | 1.6           |
| Black or African-<br>American             | 8         | 6.5     | 6.5           |
| Hispanic                                  | 24        | 19.4    | 19.4          |
| White                                     | 83        | 63.7    | 63.7          |
| Total                                     | 128       | 100.0   | 100.0         |

Table 5 provides a breakdown of the household income among the participants.

Only six (3.1%) families of the 128 total participants reported having household income below \$35,000. The most frequent range of income was \$50,000 to \$74,999 (45, 35.2%).

Of the 128 total participants, 10 (8.8%) families reported having household income over \$125,000.

Table 5

Household Annual Income

|                     | Frequency | Percent | Valid percent |
|---------------------|-----------|---------|---------------|
| Less than \$25,000  | 2         | 1.6     | 1.6           |
| \$25,001-\$34,999   | 4         | 3.1     | 3.1           |
| \$35,000-\$49,999   | 35        | 27.3    | 27.3          |
| \$50,000-\$74,999   | 45        | 35.2    | 35.2          |
| \$75,000-\$99,999   | 23        | 18.0    | 18.0          |
| \$100,000-\$124,999 | 9         | 7.0     | 7.0           |
| \$125,000-\$149,999 | 2         | 1.6     | 1.6           |
| \$150,000 or more   | 8         | 6.3     | 6.3           |
| Total               | 128       | 100.0   | 100.0         |

# **Research Questions and Hypothesis Testing**

Marriage satisfaction was measured by the Kansas Marriage Satisfaction scale. There were three questions attached to the scale, and they directly measure participants' satisfaction level of their current marriage (1 = extremely dissatisfied, and 7 = extremely satisfied). A mean of the three satisfaction scores was taken, and they were identified among the genders of the participants. Similarly, the amount of childcare responsibility and parental stress level was also examined by a series of validated questions and the mean of these questions was taken (1 = no pressure at all and 7 = very pressured by responsibilities). Table 6 is a breakdown of the marriage satisfaction and parental stress scores, as well as the age variables by participant gender.

Table 6  $Age, Satisfaction, \ and \ Stress \ Levels \ Between \ Male \ and \ Female \ Participants \ (n=128)$ 

| Gender |                | Age     | Satisfaction | Stress |
|--------|----------------|---------|--------------|--------|
| Female | N              | 83      | 79           | 79     |
|        | Mean           | 40.9221 | 4.4304       | 4.1092 |
|        | Std. Deviation | 6.41496 | 1.41033      | .74447 |
|        | Minimum        | 25.00   | 1.00         | 1.75   |
|        | Maximum        | 61.00   | 7.00         | 5.88   |
|        | Variance       | 41.152  | 1.989        | .554   |
| Male   | N              | 45      | 45           | 45     |
|        | Mean           | 43.1220 | 4.8222       | 3.8556 |
|        | Std. Deviation | 5.75411 | 1.24032      | .78740 |
|        | Minimum        | 32.00   | 2.67         | 1.00   |
|        | Maximum        | 52.00   | 7.00         | 5.38   |
|        | Variance       | 33.110  | 1.538        | .620   |
| Total  | N              | 128     | 124          | 124    |
|        | Mean           | 41.6864 | 4.5726       | 4.0171 |
|        | Std. Deviation | 6.25758 | 1.35921      | .76697 |
|        | Minimum        | 25.00   | 1.00         | 1.00   |
|        | Maximum        | 61.00   | 7.00         | 5.88   |
|        | Variance       | 39.157  | 1.847        | .588   |
|        |                |         |              |        |

Below are the breakdowns of the responses for each of the three marriage satisfaction questions, per the Kansas Marital Satisfaction Scale. Tables 7 through 9 are descriptions of the frequency of participants' responses.

Table 7

How satisfied are you with your husband (or wife) as a spouse?

|                        | Frequency | Percent | Valid percent |
|------------------------|-----------|---------|---------------|
| Extremely dissatisfied | 4         | 3.1     | 3.1           |
| Very dissatisfied      | 5         | 3.9     | 3.9           |
| Somewhat dissatisfied  | 31        | 24.2    | 24.2          |
| Mixed                  | 11        | 8.6     | 8.6           |
| Somewhat satisfied     | 38        | 29.7    | 29.7          |
| Very satisfied         | 31        | 24.2    | 24.2          |
| Extremely satisfied    | 8         | 6.3     | 6.3           |
| Total                  | 128       | 100.0   | 100.0         |

Table 8

How satisfied are you with your marriage?

|                        | Frequency | Percent | Valid percent |
|------------------------|-----------|---------|---------------|
| Extremely dissatisfied | 3         | 2.3     | 2.3           |
| Very dissatisfied      | 4         | 3.1     | 3.1           |
| Somewhat dissatisfied  | 29        | 22.7    | 22.7          |
| Mixed                  | 13        | 10.2    | 10.2          |
| Somewhat satisfied     | 39        | 30.5    | 30.5          |
| Very satisfied         | 30        | 23.4    | 23.4          |
| Extremely satisfied    | 10        | 7.8     | 7.8           |
| Total                  | 128       | 100.0   | 100.0         |

Table 9

How satisfied are you with your relationship with your husband (or wife)?

|                        | Frequency | Percent | Valid percent |
|------------------------|-----------|---------|---------------|
| Extremely dissatisfied | 4         | 3.1     | 3.1           |
| Very dissatisfied      | 7         | 5.5     | 5.5           |
| Somewhat dissatisfied  | 30        | 23.4    | 23.4          |
| Mixed                  | 10        | 7.8     | 7.8           |
| Somewhat satisfied     | 45        | 35.2    | 35.2          |
| Very satisfied         | 22        | 17.2    | 17.2          |
| Extremely satisfied    | 10        | 7.8     | 7.8           |
| Total                  | 128       | 100.0   | 100.0         |

Research Question 1 examines the differences between male and female parents' stress level as measured by the amount of childcare responsibilities. Table 10 shows an independent samples t-test, which compares the parental stress mean scores between the male and female parents. Levene's test for equality of variances was run to evaluate the equality of variance between male and female respondents, and significance score of .984 indicated that there were no differences in terms of variances between the groups. Based on the results, the t-value for group differences in terms of parental stress was t(122) = -1.79, (p=.077). This indicates that there were no significant mean differences in terms of parental stress between male and female parents although female did exhibit high stress level scores from evaluating the descriptive statistics in Table 6.

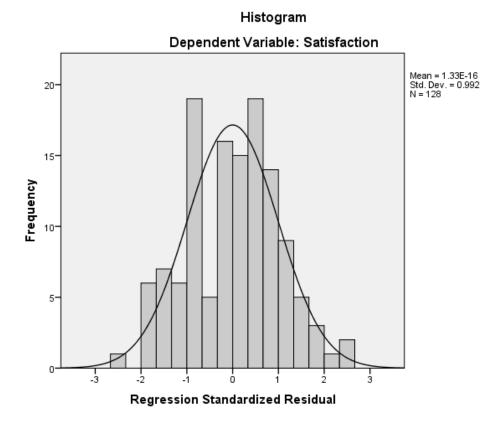
Table 10

Mean stress difference between male and female parents

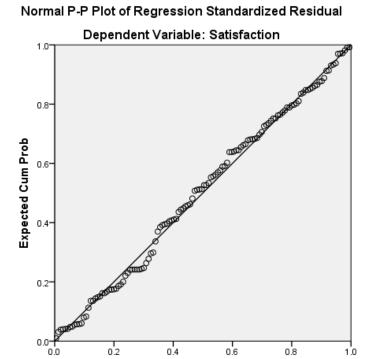
Levene's Test for
Equaility of
Variances t test for Equality of Means

|                 |      |      |       | -   | Sig.    |      |            | 95% C | I of the     |
|-----------------|------|------|-------|-----|---------|------|------------|-------|--------------|
|                 |      |      |       |     | (2-     | Mean | Std. Error | Diffe | erence       |
|                 | F    | Sig. | t     | DF  | tailed) | Dif. | Difference | Lower | <u>Upper</u> |
| Equal variances | .000 | .984 | -1.79 | 122 | .077    | 2536 | .1419      | 5346  | .0274        |
| assumed         |      |      |       |     |         |      |            |       |              |

Research Question 2 evaluates the potential contribution parental stress from the amount of childcare responsibilities has over the marriage satisfaction of parents. A multiple regression using marital satisfaction score as the dependent variable and the amount of childcare responsibilities and parental stress scores associated with childcare responsibility as the independent variables was run to test the association. Prior to the regression model, a normal distribution and a normal P-P plot were graphed to examine the normality of the variables. Based on the graphs in Figures 1 and 2, the data seemed to be normally distributed, and the normality assumptions were met for the multiple regression model. In addition, Kline (2005) discussed normality is met if the skewness value is less than 1.00 and the kurtosis value is less than 3.00. None of the skewness or kurtosis values indices exceeded ±2.00, indicating that all variables met the assumption of normality.



 $Figure\ 1.\ Normal\ distribution\ assumption\ plot.$ 



Observed Cum Prob

Figure 2. Normal P-P plot for mean satisfaction score of participants.

Tables 11 through 13 are the regression coefficient summary of the model. Based on the results presented in the table, there is sufficient evidence to support that both childcare responsibility and parental stress significantly contribute to the marriage satisfaction rate of the parents. A significant regression equation was found (F(2, 125) = 22.737, p < .000), thus, indicating that the amount of childcare responsibilities and parental stress due to caregiving significantly predict marriage satisfaction in parents. Moreover, the total variance explained for the model was found to be 26.7% (i.e.,  $R^2 = 0.267$ ).

Additionally, the unstandardized beta coefficient of parental stress was -.471, which indicates that stress and marriage satisfaction are negatively correlated, meaning as the parental stress due to childcare responsibilities increases, the satisfaction of the marriage decreases. Also, the unstandardized beta coefficient for the amount of childcare responsibilities was .347, indicating that childcare responsibilities positively influences the satisfaction of the marriage. This indicates that the more shared responsibilities a couple has, the more satisfied they tend to be with their marriage.

Table 11

Regression Model Summary

| Model | R    | R Square | Adjusted | Std. Error      |
|-------|------|----------|----------|-----------------|
|       |      |          | R Square | of the Estimate |
| 1     | .516 | .267     | .255     | 1.17857         |
|       |      |          |          |                 |

Table 12

ANOVA Results for Regression Model

| Model |            | Sum of  |     |             |                  |            |  |  |
|-------|------------|---------|-----|-------------|------------------|------------|--|--|
|       |            | Squares | df  | Mean Square | $\boldsymbol{F}$ | Sig.       |  |  |
|       | Regression | 63.163  | 2   | 31.582      | 22.737           | $.000^{b}$ |  |  |
|       | Residual   | 173.628 | 125 | 1.389       |                  |            |  |  |
|       | Total      | 236.791 | 127 |             |                  |            |  |  |
|       |            |         |     |             |                  |            |  |  |

Table 13

Multiple Regression Results for Stress and Childcare Responsibility on Marital Satisfaction

|                | Unstandarized |       | Standardized |        | Collinearity      |           |       |
|----------------|---------------|-------|--------------|--------|-------------------|-----------|-------|
|                | Coefficients  |       | Coefficients |        | <b>Statistics</b> |           |       |
|                |               | Std.  |              |        |                   |           |       |
| Model          | В             | Error | Beta         | T      | Sig.              | Tolerance | VIF   |
| 1 (Constant)   | 4.919         | .735  |              | 6.690  | .000              |           |       |
| Stress Levels  | 471           | .122  | 301          | -3.874 | .000              | .968      | 1.033 |
| Childcare      | 3.47          | .073  | .369         | 4.743  | .000              | .968      | 1.033 |
| Responsibility |               |       |              |        |                   |           |       |
|                |               |       |              |        |                   |           |       |

Lastly, the reliability analysis using Cronbach's alpha revealed that for the 3 items on the marriage satisfaction scale, The Kansas Martial Satisfaction Scale, the Cronbach's alpha was .912, which indicates a high internal consistency of the scale. For questions1 through 8 on The Sharing of Childcare Responsibilities Scale and the Parental Stress Level Scale, the Cronbach's alpha was .704, which indicates a moderate internal consistency.

## **Summary of Results**

The purpose of this quantitative research study was to examine more in depth the stressor of the amount of childcare responsibilities that parents of children diagnosed with FXS experience. This research study also examined if such stressor (amount of childcare responsibility) differs across gender among the parents of children with FXS. The relationship of parental stress due to the amount of childcare responsibility and marital satisfaction was also investigated. Therefore, this quantitative research study was designed to examine and compare parental stress as it relates to the amount of childcare responsibilities and marital satisfaction among parents of children with FXS. Based on the results, there were no significant mean differences between father's and mother's stress level when taking care of children with FXS. However, the stress and amount of childcare responsibilities from taking care of children with FXS significantly influences marital satisfaction. According to Table 13, the unstandardized beta coefficient of parental stress was -.471, meaning as the parental stress due to childcare responsibilities increases, marital satisfaction decreases. In addition, the unstandardized beta coefficient of childcare responsibilities was .347, meaning the more shared responsibilities a couple

has, the more satisfied they tend to be with their marriage. Additionally, the covariates of parental age, socioeconomic status, parent's level of education, race/ethnicity and number of years married were used to collect demographic information about the participants and they were accounted for and reported on as indicated in the tables above.

Following this chapter, is chapter 5, which will summarize this study's findings and describe its conclusions based on the results derived from the statistical analyses conducted. Chapter 5 will also present the social implications of the study as dictated by its findings, will describe the limitations of the study and will discuss future recommendation for expanding on and strengthening the research found in this area.

### Chapter 5: Discussion, Conclusions, and Recommendations

The objective of this study was to further explore the stressor around the amount of shared childcare responsibilities as it relates to the level of parental stress among parents of children diagnosed with FXS. Particularly, I strove to identify whether the stressor of childcare responsibilities differs in intensity across gender, between mother and father, and whether this difference consequentially impacts marital satisfaction. Therefore, the research was conducted to examine and compare parental stress as it relates to the amount of shared childcare responsibilities for a child (or children) diagnosed with FXS and the marital satisfaction of the parents caring for the said child, and whether a direct relationship exists between the two factors. Prior research in this subject area chiefly addressed the generality of parental stress, family functioning, and child development as they related to a child diagnosed with a pervasive developmental disorder (White & Hastings, 2004). However, there is a research gap when considering gender differences as they relate specifically to parental stress in this particular circumstance (Poop et al., 2014; Woodman et al., 2015). I sought to fill this gap by providing information about gender-specific parental stress as it relates to the caregiving responsibilities of a child diagnosed with FXS, and how the distribution of its associated stress and responsibilities may affect marital satisfaction.

This study was conducted using a quantitative research design using a multiple linear regression and independent samples *t*-test statistical analysis to examine the variables of parental stress, childcare responsibilities, and marital satisfaction as experienced by the parents of children diagnosed with FXS. The research method design

for this study entailed using an online survey, which included three subscales: the Kansas Marital Satisfaction scale to measure marital satisfaction (Schumm et al., 1983) and the Sharing of Childcare Responsibilities scale and the Parental Stress Level scale to measure the parent's level of stress (Ki & Joanne, 2014) as well as the spouse's level or amount of shared childcare responsibilities (Goff et al., 1990). The survey also gathered covariate information for demographic purposes, including (a) parental age, (b) economic status, (c) parent's level of education, (d) race/ethnicity, and (e) number of years married. All participants remained anonymous throughout the study, and no identifiable factors were linked to participants throughout the research, such as name, contact information, and address. Voluntary participants for this survey were recruited from the FXS Alliance of Texas located in the southwest region of Texas, and data were collected from October 19, 2016 through October 31, 2016.

According to the Chapter 4 results, there are no significant mean differences between the stress levels experienced by mothers and fathers caring for a child (or children) diagnosed with FXS. However, the level of stress associated with caring for a child diagnosed with FXS was found to directly impact marital satisfaction. According to the research, as the amount of parental stress increases, marital satisfaction decreases. Similarly, as the childcare responsibility increases, marital satisfaction also increases. Moreover, although there were no significant mean differences cited between the stress levels of mothers and fathers, mothers reported experiencing greater stress levels than fathers. This was demonstrated in the mean response of the average 41-year-old female who partook in this survey, who cited a 4.1092 stress rating on a 7-point Likert scale, as

compared with the average 43-year-old male who partook in this study, who cited a 3.8556 stress rating.

# **Review of the Research Problem and Purpose**

The research problem focused on the lack of research available about whether the stressor of childcare responsibilities differs across genders. As previously stated, prior researchers have explored the generality of parental stress, family functioning, and child development as it relates to a child diagnosed with FXS (White & Hastings, 2004), but there is little research considering gender differences as they relate to parental stress in this particular instance. The research purpose was to determine whether a significant mean difference in the stressor of childcare responsibilities exists across gender, and whether there is a direct relationship between the stress related to the amount of childcare responsibilities and marital satisfaction. According to Bryne (2014) and Chapman (2013), parents of children with an intellectual or developmental disorder experience at least twice as much stress as measured by the Parental Stress Index as compared to parents of typically developing children. However, there is a lack of research pertaining to the stressor of shared childcare responsibilities among parents of children diagnosed with FXS, particularly about how the stress levels differ across gender. Therefore, the purpose of this literature is to expand the research by precisely examining how stress levels of parents differ with regard to their shared childcare responsibilities and how this may or may not affect their marital satisfaction. To date, no researcher has investigated or compared the mothers' and fathers' stress levels due to childcare responsibilities

among parents of children with FXS; thus I attempted to close a gap in the existing literature pertaining to parental stress and FXS.

### **Analysis, Synthesis, and Evaluation**

This study was conducted using a quantitative research design using a multiple linear regression and an independent samples *t*-test statistical analysis. This specific research design entailed using a demographic survey that consisted of three subscales: the Kansas Marital Satisfaction scale to measure marital satisfaction (Schumm et al., 1983) and the Sharing of Childcare Responsibilities scale and the Parental Stress Level scale to measure the parents' level of stress (Ki and &Joanne, 2014) as well as the spouse's level of shared childcare responsibilities (Goff et al., 1990). The independent variables were parental stress and the sharing of childcare responsibilities, and the dependent variable was marital satisfaction. In the study focused on uncovering whether a relationship existed between the independent variables and the dependent variable as well as whether gender differences affected marital satisfaction as a result of the number of shared childcare responsibilities.

In order to conduct the research study, an official approval was obtained from the IRB at Walden University. Participants for the study were recruited from the FXS Alliance of Texas located in the southwest region of Texas. The participants were made aware of the study via a flyer, notice, or handout that was distributed to those attending monthly meetings or through the annual walk associated with the FXS Alliance of Texas, specifically in San Antonio, Texas. All participants were able to terminate their participation at any time. Due to the nature of this study, eligible participants were

required to meet the following criteria: (a) participant was the legal parent of at least one child who was diagnosed with FXS between the ages of 2 and 12, (b) participant was legally married, and (c) participant has been living with the child who was diagnosed with FXS for at least 6 months. For demographic purposes, participants were also asked to disclose the five covariates of parental age, socioeconomic status, level of education, race/ethnicity, and the number of years married. Participants were also asked to confirm their eligibility prior to completing the surveys, which was solely based on the participants' integrity and honesty. The survey yielded 132 responses, but only 128 responses met the eligibility credentials for this study. Of the participants, 98.4% identified as American, while .8% identified as Canadian, and .8% identified as Australian. The majority of the participants were female (63.7%), while 36.3% were male. Most of the participants had received a Bachelor's degree (34.7%), followed by a professional certificate (17.7%), a Master's degree (16.1%), and an associate's degree (14.5%). The participants predominately identified as Caucasian (63.7%), followed by Hispanic (19.4%), and American Indian or Alaska native (8.9%). The household annual income of participants was mainly between \$50,000 and \$79,999 (35.2%), followed by \$35,000 and \$49,000 (27.3%) and \$75,000 and \$99,999 (18.0%).

The Parent's Stress Level scale, which was used in similar research by Baxter et al. (2000) and Ki and Joanne (2014), evaluated the parents' stress level on a 7-point Likert scale ranging from 1: *do not feel any pressure or stress* to 7: *feel a lot of pressure and stress* (Baxter et al., 2000). The seven sources of stress that were evaluated included (a) accompanying the child to training in any one type of early intervention or training

center, (b) domestic training with the child, (c) allocating time between childcare and work or housework, (d) guiding the child to learn, (e) handling the emotions and behaviors of the child, (f) the differences between the development of their child and that of other children of the same age, and (g) other people's view of their childcare (Baxter et al., 2000). According to the data collected from the survey, the results indicated that there were no significant mean differences in the stress levels experienced by mothers and fathers due to the responsibilities of caring for a child diagnosed with FXS.

The Shared Childcare Responsibility scale required participants to assess their spouse's level of shared childcare responsibilities when using this scale as it was used in Goff et al.'s (1990) research. The scale also consisted of a single item measured on a 7-point Likert scale ranging from 1: does not share responsibility and they have all the responsibility to 7: sharing much responsibility, as they both have an equal shared amount of responsibilities. According to the results of the regression coefficient summary of the research model, there is sufficient evidence to show that the amount of childcare responsibilities has a direct relationship with marital satisfaction. The results indicated that as the stress from childcare responsibilities increases, marital satisfaction decreases.

The Kansas Marital Satisfaction scale, which has also been used in prior research, assessed the level of marital satisfaction in the participants (Fowers, 1991). This scale used a 7-point Likert scale. According to the study, the average female participant, who identified as 41 years old, reported a 4.4304 satisfaction rating and a 4.1092 stress rating, while the average male participant, who identified as 43 years old, reported a 4.8222

satisfaction rating and a 3.8556 stress rating. The results of this section are as follows: The majority of participants cited feeling somewhat satisfied with their husband/wife as a spouse (29.7%), followed by somewhat satisfied (24.2%), and somewhat dissatisfied (24.2%); the majority of the participants cited feeling somewhat satisfied with their marriage (30.5%), followed by very satisfied (23.4%), and somewhat dissatisfied (22.7%); and the majority of participants reported feeling somewhat satisfied with their relationship with the spouse (35.2%), followed by somewhat dissatisfied (23.4%) and very satisfied (17.2%).

## **Theoretical Implications**

#### The ABC-X Model

Hill's (1949) ABC-X model, also known as his family stress theory, is the theoretical framework that served as the guideline for this study. Since its development, this theory has been used to further understand marital outcomes and to help predict the functioning of families based on those marital outcomes (Hill, 1949). This theory is also used to describe how stressful life events within a family system can create imbalance or disturbance within said family system (Lavee & Sharlin, 1996). Hill consequentially studied family reactions to stressful life events by establishing the ABC-X model, which is composed of (A) the stressful life event, leading to (B) the effects of such stressor on the family system, which then leads to (C), the interpretation of the life event by family members, which ultimately leads to (X), the produced outcome. When specifically interpreting this theory into the context of parental stressors associated with the pressures of caring for a child diagnosed with FXS, the dynamic is as follows: (A) the child with

FXS may (B) interrupt family cohesiveness, leading to (C) the interpretation of the life event as either positive or negative and (X) the produced outcome, which depends on the family's perception of the life event (child diagnosed with FXS) and how well this life event is managed. According to Karney and Bradbury (1995), families in this situation experience marital dissatisfaction if they are unable to adapt to the stressful life event of raising a child diagnosed with FXS.

Hill's (1949) ABC-X model provides a lens with which to comprehend how a child diagnosed with FXS (a life stressor) creates stress for the parents who function as the child's caregivers. According to prior research, the parents of a child (or children) with a pervasive developmental disorder, such as FXS, are found to have significantly higher stress levels when compared with parents of typically developing children (Beckman, 1991; Beckman-Bell, 1981; Dyson, 1993; Fishman & Wolf, 1991; Johnston et al., 2003; Pisula, 2011; Poop et al., 2014; Woodman et al., 2015). This stress is due to the added responsibilities, challenges, and resources required to cope with the demands of caring for the child (Pisula, 2011).

Through the lens of the theory, the role of the child with FXS represents the (A): the stressful life event. As Hill (1949) suggested, the presence of (A) leads to the presence of (B), which is the interruption of family cohesiveness. The presence of the child diagnosed with FXS coincides with challenging behaviors and unique accommodations, which, as previously stated, contribute to the parents' stress levels and, ultimately, their marital satisfaction. Through the lens of this theory, there is the opportunity to perceive the stressor, along with the ways in which the stressor has

impacted family cohesiveness, so as to establish a better understanding. The mothers and fathers in this study were asked to assess their levels of stress on a 7-point Likert scale. According to Hill, there are seven qualities that are most relevant to maintain when faced with the (B) stage. They are (a) history and familiarity of the stressor, (b) the family's ability to put selfish acts to the side, focusing only on the best interest of the family, (c) being prideful of the family, (d) having trust, love, and unity present with the family system, (e) equal sharing of family responsibilities, (f) equal distribution of family control and decision making, and (g) strong affection of family members among all members of the family. According to Hill, when these factors remain intact, it is less likely for the (B) stage to severely disrupt the cohesiveness of the family; thus, the family is then better able to cope. Although this study suggests otherwise, prior research presented in Chapter 2 stated that a chief reason for the disruption of family cohesion and its corresponding stress is because the mother assumes the majority of the caregiver role, rather than equally assigned roles between spouses. This notion suggests that since the mother is the designated caregiver, she is assumed the majority of responsibilities pertaining to the child (e.g., Baker-Ericzen et al., 2005; Brobst et al., 2009; Hastings, 2003; Taanila et al., 1996; Woodgate et al., 2008), which may account for the higher levels of pressure reported by mothers in this study, as compared with fathers.

According to Hill's (1949) ABC-X model, in this context, (C) pertains to how the child who is diagnosed with FXS and the associated childcare responsibilities are interpreted by family members. This instance is where role responsibilities are assigned, either verbally or nonverbally, so as to divide the care of the child. This entails utilizing

the resources for the given situation and identifying family roles, rules and rituals (Patterson & Garwick, 1994). Parents are required to assess their resources, whether it is community-based, financial or familial, and divide the responsibilities amongst themselves, with regard to the other members of the family. The (C) variable is what ultimately leads to the (X) variable, which is the produced outcome, which highly depends on how the family perceives and responds to that particular life event.

According to Caplan (1964), the concept of the (X) variable can only occur if four specific elements are present. These four elements are as follow: a stressful event meriting the family's response with problem-solving techniques, the family's problem-solving technique fails, but the event is still causing undue stress; the family's undue stress increases, causing the family to seek other failing problem-solving techniques; and the crisis is ultimately identified as unbearable due to the failure of these problem-solving techniques, which increases anxiety, stress and marital dissatisfaction or discord.

The overwhelming message that is translated through Hill's (1949) ABC-X model is the ability for the family to effectively respond to the stressor. Since the stressor, (being the child diagnosed with FXS) causes a disruption to the regular pattern of family systems, the family must adjust their behaviors to best accommodate the needs of the child, other children, other family members and spouses. When spouses are unable to effectively do so, this results in increased levels of stress, which ultimately yields marital dissatisfaction and, in some cases, separation and divorce. According to prior research, the relationships that suffer ultimately fail to effectively tackle the ABC-X model and, consequentially, fail to attend to their relationship, due to their overwhelming

responsibilities of caring for their disabled child. The demands of raising a child with a developmental disorder directly affects the parent's relationship, which may cause it to suffer (Gorchoff, John & Helson, 2008; Hartley et al., 2008; Hartley et al., 2012). Not only can this outcome impact the parents' relationship, however, but the child's mental well-being as well. According to Collins, Maccoby, Steinberg, Hetherington and Bornstein (2000), the quality of the marriage can affect the development of the disabled child, particularly instances of poor communication between spouses, family dispute and marriage conflict and dissatisfaction. To establish a successful situation with regard to marital satisfaction and the disabled child, it is imperative to comprehend the reasons that underlie a particular outcome (X), and the ways to produce a more efficient outcome for all parties involved.

# **Conclusive Findings**

Raising a child with a developmental disorder and its associated stressors can uniquely impact the child's mother and father marital satisfaction. According to the research present in this study, as well as the Hill's (1949) ABC-X theory, the presence of parental stress due to the child may result in a spillover effect, which can ultimately disperse said parent's stress on the rest of the family members. This stress can directly impact marital satisfaction, as is evidenced through this study, as well as the mental well-being of the child and other family members. The level of stress experienced by the parents can also cause the parents to place the needs of the child before their own needs or that of their spouses, which can result in increased feelings of marital dissatisfaction.

### **Research Questions**

To address the research problem, the study focused on two particular questions:

RQ1: How does the perceived level of stress around shared childcare responsibilities of mothers and fathers of children with FXS differ?

RQ2: What is the relationship between the level of stress of parents of children with FXS and the amount of shared childcare responsibilities and marital satisfaction?

Interpretation of Findings: Conclusions (Q1)

Children with developmental disorders are highly dependent on their parents for an extended period of time. This dependency adds pressure to the parents, who must assume a long-term, intensive caregiver role for their child (Harris, 1948; Hartley et al., 2008). These parents are also faced with situation-specific responsibilities that parents of typically developing children may not encounter, such as the recruitment of community-based programs and services, tackling significant behavioral problems, carrying out additional childcare responsibilities and facing new stages of developmental growth and uncertainty (Long, 2009).

The term "parental stress" has yielded many definitions, one of which include the parent's response to life situations and high demands to life crises or events that involve both physiological and psychological reactions that can be either instantaneous or delayed (Donovan, 1988). In the case of parental stress as it relates to a child diagnosed with a pervasive developmental disorder like FXS, there has been ample research about how the parental stress impacts the mother, but very little to no research about the affect has been focused on the father. Prior research has assumed that mothers tend to assume

the majority of the parenting responsibilities, as traditionally the mother assumed the childcare and household duties while the father assumed the financial responsibilities. However, as a result of this role assumption, these mothers have consequentially been found to exhibit the greatest forms of psychopathological problems as it relates to this parental stress (e.g. Brobst et al., 2009; Oelofsen & Richardson, 2006). Unlike mothers, the fathers' stress is not directly associated with the child, but rather, with the stress levels exhibited by his partner (Hastings et al., 2005). For instance, if the mother was experiencing high levels of stress and depression, this significantly influenced the father's stress levels (Hastings et al., 2005).

Although there is research to be found about parental stress as it pertains to mothers of children with pervasive developmental disorders, there is little research to be found about the challenges and stressors of fathers. However, according to the data uncovered in this study, both mothers and fathers encounter similar levels of stress with regards to the caring for their child who is diagnosed with FXS. It was also noted in this study, that the mothers cited additional level of stress, which may be due, in part, to the mother assuming majority of the caregiver roles, or perceiving the child's behavioral, emotional and physical demands to be of priority (Hartley et al., 2012). There remains much room for future research to determine the exact nature of the stresses encountered by such mothers and fathers. Nonetheless, for the purposes of this study, we fail to reject the first null hypothesis (H1<sub>0</sub>): there are no statistically significant mean differences between mothers' and fathers' parenting stress levels due to their shared childcare responsibilities as measured by the shared childcare responsibilities scale.

# **Interpretation of Findings: Conclusions (Q2)**

When parents tend to experience elevated stress levels, a psychological spillover effect may occur, which is when another person's stress becomes problematic for the whole family system. Consequentially, psychological spillover of one parent, as related to the stress associated with caregiving for their developmentally disabled child, can yield problems between parents and their non-disabled child (or children), problems between parents and other family members, marital dissatisfaction, marital separation or divorce and financial hardships (Jesser, 2003). Moreover, difficult behavioral characteristics on behalf of the child, such as anxiety, social avoidance, isolation, irritability, repetitive motor behaviors, high activity levels and difficulty coping with unexpected changes can make these parental responsibilities even more difficult (Abbeduto, Brady & Kover, 2007).

The pressures and stress related to caregiver responsibility may also cause the parent to place his/her child's needs before the needs of their spouse (Gorchoff et al., 2008). This responsibility tradeoff can yield even greater levels of stress and tension in the relationship, resulting in decreased levels of intimacy and overall marriage dissatisfaction (Brobst et al., 2009; Gau et al., 2012; Taanila, Kokonen & Jarvelin, 1996). Despite the parents' resources to manage their stress, the caregiving pressures oftentimes impact the marital relationship (e.g. Johnson et al., 2003; McCarthy, Cuskelly, Kraayenoord & Cohen, 2006). According to Brobst et al. (2009), parents of these children, preoccupied with the needs of their child, struggle with creating ample time to attend to both their disabled child and their partner. Consequentially, the divorce rate of

these parents, according to prior research, is significantly higher than parents of typically developing children, with statistical risk for divorce remaining consistent across all ages of the child (Hartley, Barker Selzter, Greenberg, Floyd & Orsmond, 2010).

Moreover, although prior research has explored how developmental disorders in children, such as autism, impact marital satisfaction, there is also little research about how caregiving for children with FXS specifically impacts marital satisfaction.

According to the research uncovered in this study, parental stress due to the amount of childcare responsibilities associated with the child diagnosed with FXS is directly related to marital satisfaction. The results of this study, indicated that as the amount of parental stress increases, marital satisfaction decreases. Correspondingly, as the amount of childcare responsibility increases, marital satisfaction also increases. For the purposes of this study, we reject the second null hypothesis (H2o): the level of stress of parents of children with FXS will not significantly predict marital satisfaction, as measured by the level of shared childcare responsibilities of parents of children with FXS will not significantly predict marital satisfaction.

Much of the attention that is devoted to the child is at the expense of the spouse. For example, according to Brobst et al. (2009), parents of children with disabilities face challenges with finding time to devote to both their disabled child and their partner. Moreover, according to Levinger and Huston (1990), one area that creates the most conflict within marriages is with regard to the role of parenting. According to Willoughby and Glidden (1955), these issues can be resolved simply through the equal

sharing of parental stress, childcare responsibilities and the burden of caretaking, which alleviates the intense pressures experienced by assigning the majority of responsibilities to one parent.

## **Limitations of the Study**

This study had severe topical limitations. There is a lack of information pertaining to paternal stress and childcare responsibilities and their effect on marital satisfaction pertaining to the parents of children who are diagnosed with a pervasive developmental disorder. There is even less information about how these factors relate to the parents of children diagnosed with FXS. According to Hagerman (2002) and Sullivan et al. (2006), most of the research that exists about children diagnosed with FXS relates to specific behavioral problems, such as hyperactivity, inattention, temperament and aggression. Very few research studies have deeply explored the dynamics of children diagnosed with FXS, especially the impact of the responsibilities that children diagnosed with FXS have on their caregiving parents. Much of the available information about children and developmental disorders is linked to autism-spectrum disorders, as they are more common.

When conducting this study, where was no literature located about parents of children with FXS, paternal stress and marital satisfaction. In this sense, the study did not have ample material to use as a point of reference. Most of the information that was located about parental stress as it relates to childcare responsibilities also chiefly related to mothers, and there was little to no information about the roles, emotions or responsibilities experienced by fathers as they associated with this topic. To date, no

research study has investigated or compared the mothers' and fathers' stress levels due to childcare responsibilities among parents of children with FXS, thus this study will attempt to close a gap in the existing literature pertaining to parental stress and FXS.

Moreover, there remains limited information about stress levels across gender in general, which provides little means for a point of reference for the gender-based differences.

This study, again, functioned as the first study that brought all of these topics, which had received little attention, to the forefront.

#### Recommendations

The key recommendations in conclusion of this study are to further research the topic of shared childcare responsibilities, corresponding gender-based parental stress between mothers and fathers and overall marital satisfaction as it relates to caring for a child diagnosed with FXS. As a great deal of information is still lacking in this subject area, the focus would be to expand the existing body of knowledge, in hopes of providing more material for parents and health care professionals alike. The only means of collecting this information is by continuing to gather more data about this topic, whether through the means suggested above, or through other means. More information is needed to explore this very specific topic in order for a remedy, perhaps one that is therapeutic in nature, can help resolve the stressors encountered between husband and wife as a result of the responsibilities associated with caring for a child diagnosed with FXS.

#### **Recommendations for Future Research**

Future research regarding this study should include a second, perhaps larger, assessment of mother and father responsibilities and levels of stress as they relate to

raising a child diagnosed with FXS. Perhaps, a sequential study could be twice as large in size (approximately 250 people), which may provide better insight into the trends that are evident within these familial situations. Additionally, a second study could be conducted at organizations that are headquartered on the East Coast and the West Coast, as perhaps the results may be different, depending on lifestyle and temperamental trends that may exist outside of the Texas area.

Another study could potentially include a moderating model where perhaps parental gender or childcare responsibilities could serve as a moderator to further examine how these variables may impact parental stress or marital satisfaction. Another suggestion for a future study could potentially examine the individual questions about parental stress and shared childcare responsibility from The Sharing of Childcare Responsibilities Scale and the Parental Stress Level Scale. It would be interesting to investigate if there are any significant mean differences between the different kinds of stress found in this scale, versus, just examining the overall score of the scale. This scale, specifically looks at parent's stress levels and it was designed to evaluate the overall score of parent's stress level on a 7-point Likert scale ranging from 1: do not feel any pressure or stress to 7: feel a lot of pressure and stress (Baxter et al, 2000). The seven sources of stress that were evaluated were the following: 1) accompanying child to training in any one type of early intervention class or training center 2) domestic training with child, 3) allocating time between child care and work or housework, 4) guiding child to learn, 5) handling the emotions and behaviors of child, 6) the differences between the development of their child and that of other children of the same age, and 7) other

people's view of their child care (Baxter et al., 2000) but again, analyzing each individual question could potentially add to the body of literature pertaining to parental stress among parents of children with developmental disorders.

In addition, another possible future study could examine different variables that may potentially affect the manner in which a family perceives the life event of having a child diagnosed with FXS. This could potentially expand and incorporate the theory guiding and supporting this research study, Hill's Family System Theory of Family Stress, specifically looking at the ABC-X model. For example, a future study could incorporate investigating how financial support, availability of resources, community and social support or lack of such factors may affect the manner in which a family perceives the life event of having a child diagnosed with FXS and how that may or may not affect their family dynamics and relationships.

Going forward, it is also imperative to include more male participants in future studies. As this study aimed to collect information about how raising a child diagnosed with FXS impacts fathers, only about one-third of the study's participants were male, which translates to approximately 45 participants. In the grand scheme of studying this phenomenon, 45 male participants are surely not enough to provide substantial data. Perhaps, there could be future studies established to solely focus on gathering male responses, opinions and perceptions. Furthermore, to gather more information about how raising a child with FXS and its associated stress impacts marital satisfaction, future studies may include focus groups. Married couples could be asked to respond to a few previously established questions, both together and separately, to record which instances

they believe to have greatly affected their marriage and how they collaborate on matters that entail resolving responsibility pressures, frustrations and moments of crises, whether behavioral, emotional or physical, all relating to their disabled child. The focus groups may provide a great deal of insight into the emotions that are involved in this caregiving process, and how said emotions affect the spouse.

### **Implications of Findings**

The results indicate that contrary to prior research, mothers and fathers experience a similar level of parental stress in regards to the caregiving responsibilities for their child diagnosed with FXS. However, the research indicates that mothers feel a greater sense of stress in regards to the associated childcare responsibilities than the fathers. Moreover, the research indicates an inversed correlation between the pressures encountered from the responsibilities associated with caring for a child diagnosed with FXS and the level of marital satisfaction. All of these factors collectively demonstrate Hill's (1949) ABC-X model, which is the theoretical framework that guides this study.

## **Significance of Study**

The results of this study are beneficial to parents of children diagnosed with a developmental disorder, particularly FXS and researchers and professionals exploring the topic. This study is also significant to the health care field particularly that of mental health, as it will provide more insight into the demands of the caregiving responsibilities that parents endure due to the raising of their child with a developmental disability (Poop et al., 2014; Woodman et al., 2015). This is the first research study conducted that considers the variables of parental stress and marital satisfaction due to childcare

responsibilities, and one of very few studies that considers parental stress as it relates to children diagnosed with FXS, and how the associated pressures can affect marital satisfaction. This study strives to lay the foundation for future research as to how different stressors may affect marital satisfaction among the parents of children with FXS, as well as the relationships between parental stress across genders, shared childcare responsibilities and marital satisfaction. It also seeks to provide an understanding about how added pressure is generally experienced not only by the mother but also by the father, and why.

This study will provide theoretical implications, particularly focusing on that of Hill's (1949) ABC-X theory, add to existing knowledge about this topic and further the understanding of the significance of specialized programs and therapeutic assistance that is provided for parents with children who are diagnosed with FXS. This study will also contribute to improvements in treatment, therapeutic approaches and predicted outcome, and help to develop more effective parental stress interventions so as to improve stress-related outcomes for parents. Ultimately, this study exists to lay the groundwork for future studies pertaining to this specific topic, and increase the body of knowledge available about parental stress that is unique to both (father and mother) and how said stress affects marital satisfaction, particularly pertaining to the caregiving of children with developmental challenges.

Overall, this study is significant to the health care field, specifically that of mental health. When caring for a child that is diagnosed with FXS, much of the attention is focused on the child at the expense of the parent's, who function as the caregivers, thus,

possibly affecting their psychological wellbeing. According to this study, parents in this situation utilize their resources to improve their child's wellbeing, which can be detrimental to other areas of their lives, like their marriage. With the availability of more information pertaining to the phenomena explored in this study, there is a greater potential to improve the communication avenues that exist among the child's parents, so as to strive for marital satisfaction, a stable living environment for the child and a situation that best accommodates the needs of the child and the involved parents and their partnership.

#### **Summary**

This chapter presented a discussion about the study, its implications and an analysis of the results pertaining to the stressor of shared childcare responsibilities as it relates to the parents of children diagnosed with Fragile X Syndrome. The research particularly strove to identify whether the amount of childcare responsibilities differs in intensity across gender (between mother and father) and whether this difference consequentially impacts marital satisfaction. The primary objective of this study was to expand the body of knowledge about the stressor of shared childcare responsibilities as it relates to the parents of children diagnosed with Fragile X Syndrome, as existing information about this topic is severely limited. A quantitative research design utilizing a multiple linear regression and independent samples *t*-test analysis was selected for this study, as it enabled for the interpretation of survey-based results. The results of the study indicated that a significant mean difference exists between parental stress associated with the amount of shared childcare responsibilities and marital satisfaction. On the other

hand, the study did not find a significant mean difference in the level of parental stress that was experienced uniquely by mothers and fathers of children diagnosed with FXS. Lastly, for future studies, recommendations include conducting larger surveys in other areas of the country, conduct surveys that more strongly emphasize the male (father) feedback and perhaps include focus groups as well in efforts to collect profound information and insight about the couple's marital experience as it pertains to raising a child diagnosed with FXS.

#### References

- Abbeduto, L., Brady, N., & Kover, S. (2007). Language development and Fragile X syndrome: Profiles, syndrome-specificity, and with-syndrome differences. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(1), 36–46. doi:10.1002/mrdd.20142
- Abrahams, B. S., & Geschwind, D. H. (2010). Connecting genes to brain in the autism spectrum disorders. *Archives of Neurology*, 67(4), 395-399. doi:10.1001/archneurol.2010.47.
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, D.C.: Author.
- Angell, R. (1936). *The family encounters the Depression*. New York, NY: Charles Scribner.
- Asberg, K. K., Vogel, J. J., & Bowers, C. A. (2008). Exploring correlates and predictors of stress in parents of children who are deaf: Implications of perceived social support and mode of communication. *Journal of Child and Family Studies*, *17*(1), 486-499. doi:10.1007/s10826-007-9169-7
- Baker, B. L., & Heller, T. L. (1996). Preschool children with externalizing behaviors: Experience of fathers and mothers. *Journal of Abnormal Psychology*, 24(4), 513-532. doi:10.1007/bf01441572
- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Preschool children with and without developmental delay: behavior problems and

- parenting stress over time. *Journal of Intellectual Disability Research*, 47(4-5), 217-230. doi: 10.1046/j.1365-2788.2003.00484.x
- Baker, D. B., & McCal, K. (1995). Parenting stress in children with attention-deficit hyperactivity disorder and parents of children with learning disabilities. *Journal of Child and Family Studies*, 4(1), 57-68. doi:10.1007/bf02233954
- Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and Adaptability in parents of toddlers with and without autism spectrum disorders.

  \*Research and Practice for Persons with Severe Disabilities, 30(4), 194-204. doi: 10.2511/rpsd.30.4.194
- Barker, E. T., Hartley, S. L., Seltzer, M., Floyd, F. J., Greenberg, J. S., & Orsmond, G. I. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology*, 47(2), 551-561. doi:10.1037/a0021268
- Baxter, C., Cummins, R. A., & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual & Developmental Disability*, 25(2), 105-118. doi:10.1080/13269780050033526
- Beckman-Bell, P. J. (1981). Child-related stress in families of handicapped children.

  Topics in Early Childhood Special Education, 1(3),45-53.

  doi:10.1177/027112148100100310
- Beckman-Bell, P. J. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without a disability. *American Journal on Mental Retardation*, 95(5), 585-595.

- Bellows, A. (2014). *Maternal views and their impact to high-stakes testing* (Doctoral dissertation). Available from ProQuest Dissertations & Theses Full Text database. (UMI No. 3643791)
- Bitsika, V., & Sharpley, C. F. (2004). Stress, anxiety and depression among parents of children with autism spectrum disorder. *Australian Journal of Guidance & Counselling*, *14*(2), 151-161. doi:10.1017/s1037291100002466
- Boss, P., & Greenberg, J. (1984). Family boundary ambiguity: A new variable in family stress theory. *Family Process*, 23(4), 535-546. doi:10.1111/j.1545-5300.1984.00535.x
- Boss, P. (1987). Family stress. In M. B. Sussman & S. K. Steinmets (Eds.), *Handbook of marriage and the family* (pp. 695-723). New York, NY: Plenum Press.
- Botello, J. (2014). Combat-related posttraumatic stress disorder: Locus of control and marital satisfaction (Doctoral dissertation). Available from ProQuest Dissertations & Theses Full Text database. (UMI No. 3669566)
- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 17(4), 208-215. doi:10.1177/10883576020170040301
- Brannen, J., & Moss, P. (1991). Managing mothers: Dual earner households after maternity leave. London, England: Unwin Hyman.
- Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology*, 24(3), 441-451. doi:10.1037/0012-1649.24.3.441\_

- Britner, P. A., Morgan, M. C, Planta, R. C, & Marvin, R. S. (2003). Stress and coping: A comparison of self-report measures of functioning in families of young children with cerebral palsy or no medical diagnosis. *Journal of Child & Family Studies*, 12(3), 335-348.
- Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities*, 24(1), 38-49. doi:10.1177/1088357608323699
- Budig, M. J., & Folbre, N. (2004). *Activity, proximity, or responsibility? Measuring parental childcare time*. In N. Folbre & M. Bittman (Eds.), *Family time: The social organization of care* (pp. 51–68). New York, NY: Routledge.
- Burr, W., & Kleins, S. (1994). *Reexamining family stress*. Thousand Oaks, CA: Sage Publications.
- Byrne, N. E. (2014). *Parental cognitions, stress and coping in parents of children with developmental disabilities* (Doctoral dissertation). Available from ProQuest Dissertations & Theses Full Text database. (UMI No. U613976).
- Cao, X., Jiang, X., Li, X., Hui Lo, M. C., & Li, R. (2013). Family functioning and its predictors among disaster bereaved individuals in china: Eighteen months after the Wenchuan earthquake. *PloS One*, 8(4), e60738.

  doi:10.1371/journal.pone.0060738\_
- Caplan, G. (1964). Principles of preventive psychiatry. New York, NY: Basic Books.
- Carey, W. B., & McDevitt, W. B. (1978). Revision of the infant temperament questionnaire. *Journal of Pediatrics*, 61, 735-739.

- Caro, D. H., & Cortes, D. (2012). Measuring family socioeconomic status: An illustration using data from PIRLS 2006. *The Monograph Series: Issues and Methodologiesin Large Scale Assessments*, 1(5), 9-35.
- Cavan, R., & Ranck, K. (1938). *The family and the Depression*. Chicago, IL: University of Chicago Press.
- Centers for Disease Control and Prevention. (2006). *Monitoring Developmental Disabilities*. Retrieved from http://www.cdc.gov/ncbddd/dd/ddsurv.htm
- Chapman, M. (2013). An investigation into the parental stress levels of families who have children with severe developmental disabilities using residential short breaks: A contributing factor of its stress reduction impact (Doctoral dissertation).

  Available from ProQuest Dissertations & Theses Full Text database. (UMI No. U610252).
- Civick, P. D. (2008). Maternal and paternal differences in parental stress levels and marital satisfaction levels in parents of children diagnosed with autism spectrum disorders (Doctoral dissertation). Available from ProQuest Dissertations & Theses Full Text database. (UMI No. 3311811).
- Clifford, S., Dissanayake, C., Bui, Q.M., Huggins, R., Taylor, A.K., & Loesch, D.Z. (2007). Autism spectrum phenotype in males and females with fragile X Mutation and permutation. *Journal of Autism and Developmental Disorders*, 37(4), 738-747. doi:10.1007/s10803-006-0205-z
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.

- Cohen, J., & Cohen, P. (1983). Applied multiple regression/correlation analysis for the behavioral sciences (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum.
- Cohen, D., Pichard, N., & Tordjman, S. (2005). Specific genetic disorders and autism: Clinical contribution towards their identification. *Journal of Autism and Developmental Disorders*, 35(1), 103-116. doi:10.1007/s10803-004-1038-2
- Coie, J. D., &Asher, S. R. (1996). *Peer rejection in childhood*. Cambridge, England: Cambridge University Press.
- Collins, W. A., Maccoby, E. E., Steinberg, L., Hetherington, E. M., & Bornstein, M. H. (2000). Contemporary research on parenting: The case for nature and nurture.

  \*American Psychologist\*, 55(2),218-232. doi:10.1037/0003-066X.55.2.218
- Coltrane, S. (2000). Research on household labor: Modeling and measuring the social embeddedness of routine family work. *Journal of Marriage and the Family*, 62(4), 1208–1233. doi:10.1111/j.1741-3737.2000.01208.x
- Cooper, D. R., & Schindler, P. S. (2006). *Business Research Methods*. Ninth ed. Boston: McGraw Hill Irwin.
- Crane, D.R., Middleton, K.C., & Bean, R.A. (2000). Establishing criterion scores for the Kansas marital satisfaction scale and revise dyadic adjustment scale. *American Journal of Family Therapy*, 28(1), 53-60. doi:10.1080/019261800261815
- Crowley, S. L., & Taylor, M. (1994). Mothers' and fathers' perception of family functioning in families having children with disabilities. *Early Education and Development*, 5(3),213-225. doi:10.1207/s15566935eed0503\_3

- Cummings, S. T. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and chronically ill children. *American Journal of Orthopsychiatry*, 46(2),246-255. doi:10.1111/j.1939-0025.1976.tb00925.x
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38(7),1278-1291. doi:10.1007/s10803-007-0512-z
- Delambo, D., Chung, W. & Huang, W. (2011). Stress and age: A comparison of Asian American and non-Asian American parents of children with developmental disabilities. *Journal of Developmental and Physical Disabilities* (23)2, 129-141. doi:10.1007/s10882-010-9211-3
- Deutsch, F. M. (1999). *Halving it all: How equally shared parenting works*. Cambridge, MA: Harvard University Press.
- Dissanayake, C., Bui, Q., Bulhak-Paterson, D., Huggins, R., & Loesch, D. Z. (2009).

  Behavioural and cognitive phenotypes in idiopathic autism versus autism associated with fragile X syndrome. *Journal of Child Psychology and Psychiatry*, 50(3), 290-299.doi:10.1111/j.1469-7610.2008.01988.x
- Donovan, C. A. (1988). Family stress and ways of coping with adolescents who have handicaps: Maternal perceptions. *American Journal of Mental Retardation*, 92(6), 502-509.
- Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism,

- Down syndrome, behavior disorders, and normal development. *Exceptionality*, 2(2),97-110. doi: 10.1080/09362839109524770
- Dumas, J. E., & Wekerie, C. (1995). Maternal reports of child behavior problems and personal distress as predictors of dysfunctional parenting. *Development & Psychopathology*, 7(3), 465-479. doi:10.1017/s0954579400006635
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, *37*(1), 39-52. doi:10.1023/a:102659230543680478.73
- Dutra, C. M. (1999). Need levels as correlates of stress and marital satisfaction in families raising a child with autism. Unpublished doctoral dissertation, California State University, Long Beach.
- Dyson, L. L. (1991). Families of young children with handicaps: Parental stress and family functioning. *American Journal on Mental Retardation*, 95(6),623-629.
- Dyson, L. L. (1993). Response to the presence of a child with disabilities. Parental stress and family functioning over time. *American Journal on Mental Retardation*, 98(2), 207-218.
- Dyson, L. L. (1997). Families of young children with handicaps: Parental stress and family functioning. *American Journal on Mental Retardation*, 95(6), 623-629.
- Eibach, R. P., & Mock, S. E. (2011). Idealizing parenthood to rationalize parental investments. *Psychological Science*, 22(2), 203–208. doi:10.1177/0956797610397057

- Eisenhower, A.S., Baker, B.L., & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behavior problems, and maternal well-being.

  \*\*Journal of Intellectual Disability Research, 49(9), 657-671. doi:10.1111/j.1365-2788.2005.00699.x\*
- Ellis, J., & Hirsch, J. (2000). Reasons for living in parents of developmentally delayed children. *Research in Developmental Disabilities*, 21(4), 323-327. doi:10.1016/s0891-4222(00)00045-7
- Erel, O., & Burman, B. (1995). Interrelatedness of marital relations and parent-child relations: A meta-analytic review. *Psychological Bulletin*, *118*(1), 108-132. doi:10.1037/0033-2909.118.1.108.
- Esdaile, S. A., & Greenwood, K. M. (2003). A comparison of mothers' and fathers' experience of parenting stress and attributions for parent-child interaction outcomes. *Occupational Therapy International*, 10(2), 115-126. doi:10.1002/oti.180
- Fernandez-Carvajal, I., Walichiewicz, P., Xiaosen, X., Pan, R. Hagerman, P.J. & Tassone, F.(2009). Screening for expanded alleles of the *FMR1* gene in blood spots from newborn males in a Spanish population. *Journal of Molecular Diagnostics*, 11(4), 324-329. doi:10.2353/jmoldx.2009.080173
- Fineman, M. A. (2009). Evolving images of gender and equality: A feminist journey.

  New England Law Review, 43, 101–123.
- Fisman, S. N., Wolf, L. C., & Noh, S. (1989). Marital intimacy in parents of exceptional children. *The Canadian Journal of Psychiatry*, 34(6), 519-525.

- Fisman, S., & Wolf, L. C. (1991). The handicapped child: Psychological effects of parental, marital, and sibling relationships. *Psychiatric Clinics of North American*, 14, 199-217.
- Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*, 46(4), 359-371. doi:10.2307/585096
- Foa, U., & Foa, E. (1974). *Societal structures of structures of the mind*. Springfield, IL: Charles C. Thomas.
- Folbre, N., & Bittman, M. (2004). Family time: The social organization of care. London: Routledge.
- Fowers, B. J. (1991). His and her marriage: A multivariate study of gender and marital satisfaction. *Sex Roles*, 24(3-4), 209-221. doi:10.1007/bf00288892
- Frank, S. J., Olmsted, C. L., Wagner, A. E., Laub, C. C, Freeark, K., Breitzer, G. M., et al. (1991). Child illness, the parenting alliance, and parenting stress. *Journal of Pediatric Psychology*, *16*(3), 361-371. doi: 10.1093/jpepsy/16.3.361
- Frankfort-Nachmias, C., & Nachmias, D. (2008). Research methods in the social sciences (7th ed.). New York: Worth.
- Frey, K. A., Greenberg, M. T., & Fewell, R. R. (1989). Stress and coping among parents of handicapped children. A multidimensional approach. *Journal on Mental Retardation*, *94*(3), 240-249.
- Foulard, W., McDevitt, S.C., Carey, W.B. (1984). Assessing temperament in one-to three-year old children. *Journal of Pediatric Psychology*, *9*(2), 205-217.

- doi:10.1093/jeeps/9.2.205
- Gallagher, J. J., Beckman, P., & Cross, A. H. (1983). Families of handicapped children: Sources of stress and its amelioration. *Exceptional Children*, *50*, 10-19.
- Gau, S., Chou, M., Chiang, H., Lee, J., Wong, C., Chou, W., & Wu, Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6(1), 263-270. doi:10.1016/j.rasd.2011.05.007
- Goff, S. J., Mount, M. K., & Jamison, R. L. (1990). Employer supported childcare, work/family conflict, and absenteeism: A field study. *Personnel Psychology*, 43(4), 793-809. doi:10.1111/j.1744-6570.1990.tb00683.x
- Goldberg, A. E. (2013). "Doing" and "undoing" gender: The meaning and division of housework in same-sex couples. *Journal of Family Theory & Review*, *5*(2), 85–104. doi:10.1111/jftr.12009
- Goldsmith, H.H., & Rothbart, M.K. (1996). *The laboratory temperament assessment BatteryLAB-TAB*). Madison, WI: University of Wisconsin.
- Gorchoff, S. M., John, O. P., & Helson, R. (2008). Contextualizing change in marital Satisfaction during middle age: An 18-year longitudinal study. *Psychological Science*, 19(11), 1194-1200. doi:10.1111/j.1467-9280.2008.02222.x
- Gornick, J., & Meyers, M. (2009). Gender equality: Transforming family divisions of labor. New York: Verso Books.
- Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health & Illness*, *15*(1), 102-120. doi: 10.1111/1467-9566.ep11343802

- Gray, D. E., & Holden, W. J. (1992). Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities*, 18, 83-93.
- Gupta, V. B. (2007). Comparison of parenting stress in different developmental disabilities. *Journal of Developmental and Physical Disabilities*, 19(4), 417-425. doi: 10.1007/s10882-007-9060-x.
- Hadadian, A. (1994). Stress and social support in fathers and mothers of young children with and without disabilities. *Early Education and Development*, *5*(3), 226-235. doi:10.1207/s15566935eed0503\_4
- Hagerman, R. J., & Cronister, A. (1996). *Fragile X syndrome: Diagnosis, treatment, and research*, (2nd Ed), Baltimore, MD: Johns Hopkins University Press.
- Hagerman, R. J. (2002). The physical and behavioral phenotype. In R. J. Hagerman & P.
  J. Hagerman (Eds.), *Fragile X Syndrome: Diagnosis, Treatment, and Research Third Edition* (3rd ed., pp. 3-87). Baltimore, MD: Johns Hopkins University Press.
- Hagerman, R. J., & Hagerman, P. (Eds.). (2002). *Fragile X syndrome: Diagnosis,*treatment, and research (3rd ed.). Baltimore, MD: Johns Hopkins University

  Press.
- Hagerman, R. J. (2006). Lessons from fragile X regarding neurobiology, autism, and neurodegeneration. *Journal of Developmental Behavioral Pediatrics*, 27(1):63-74. doi:10.1097/00004703-200602000-00012

- Hagerman, P. (2008). The fragile X prevalence paradox. *Journal of Medical Genetics*, 45(8), 498-499. doi:10.1136/jmg.2008.059055
- Hagerman, R. J., Au, J., & Hagerman, P. (2011). FMR1 premutation and full mutation Molecular mechanisms related to autism. *Journal of Neurodevelopmental Disorders*, *3*(3), 211-224.doi:10.1007/s11689-011-9084-5
- Hagerman, R. J., Narcisa, V., & Hagerman, P. J. (2011). Fragile X: A molecular and treatment model for autism spectrum disorders. In D. G. Amaral, D. H.Geschwind & G. Dawson (Eds.), Autism Spectrum Disorders. New York: Oxford University Press.
- Harris, S. L. (1984). The family and the autistic child: A behavioral perspective. *Family Relations*, 33(1), 127-134. doi:10.2307/584597
- Hartley, S. L., Sikora, D. M., & McCoy, R. R. (2008). Prevalence and risk factors of Maladaptive behaviour in young children with Autistic Disorder. *Journal Of Intellectual Disability Research*, 52(10), 819-829. doi:10.1111/j.1365-2788.2008.01065.x
- Hartley, S. L., Barker, E. T., Baker, J. K., Seltzer, M. M., & Greenberg, J. S. (2012).

  Marital satisfaction and life circumstances of grown children with autism across 7 years. *Journal of Family Psychology*, 26(5), 688-697. doi: 10.1037/a0029354
- Hartley, S. L., Barker, E. T., Seltzer, M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt,
  D.(2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 44-457.
  doi:10.1037/a0019847

- Hartley, S. L., Erin, T. B., Marsha, M. S. & Greenberg, J. S. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal on Intellectual and Developmental Disabilities*, 116(1), 81-95. doi:10.1352/1944-7558-116.1.81
- Hastings, R. P. (2003). Child behavior problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research*, 47(4-5), 231-237. doi:10.1046/j.1365-2788.2003.00485.x
- Hastings, R.P., Kovshoff, H., Ward, N.J., Espinosa, F.D., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-schoolchildren with Autism. *Journal of Autism and Developmental Disorders*, 35(5), 635-644.doi: 10.1007/s10803-005-007-8
- Hatton, D. D., Bailey, D.B., Hargett-Beck, M.Q., Skinner, M., & Clark, R.D. (1999).

  Behavioralstyle of young boys with fragile x syndrome. *Developmental Medicine*& Child Neurology, 41(9), 625-632. doi:10.1111/j.1469-8749.1999.tb00666.x
- Hatton, D.D., Hooper, S.R., Bailey, D.B., Skinner, M., Sullivan, K. & Wheeler, A. (2002). Problem behavior in boys with fragile X syndrome. *American Journal of Human Genetics* 108(2), 105–116. doi:10.1002/ajmg.10216
- Hatton, D.D., Sideris, J., Skinner, M., Mankowski, J., Bailey, D.B., Roberts, J., *et al.* (2006). Autistic behavior in children with fragile X syndrome: prevalence, stability, and the impact of FMRP. *American Journal of Medical Genetics* 140A(17), 1804–1813.doi: 10.1002/ajmg.a.31286
- Hauser-Cram, P., Warfield, M., Shonkoff, J., & Kauss, M. (2001). Children with

- disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development, 66*, 120-131.
- Hawley, C. A., Ward, A. B., Magney, A. R., & Long, J. (2003). Parental stress and burden following traumatic brain injury amongst children and adolescents. *Brain Injury*, 17, 1-23. doi:10.1080/0269905021000010096
- Hegvik, R.L., McDevitt, S.C., Carey, W.B. (1982). The middle childhood temperament questionnaire. *Journal of Development and Behavioral Pediatrics*, *3*(4), 197-200. doi: 10.1097/00004703-198212000-00004
- Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, *9*(2), 125-137. doi:10.1177/1362361305051403
- Hill, R. (1949). Families under stress. Westport, Conn: Greenwood Press.
- Hill, R. (1958). Generic features of families under stress. Social Casework, 39, 139-158.
- Hill, R. (1966). Contemporary developments in family theory. *Journal of Marriage and the Family*, 28(1), 10-25. doi:10.2307/350035
- Hochschild, A. R., & Machung, A. (2012). *The second shift* (2nd ed.). New York: Penguin Books.
- Hodapp, R. M., Ricci, L. A., Ly, T. M., & Fidler, D. J. (2003). The effects of the child with down syndrome on maternal stress. *British Journal of Developmental*\*Psychology, 21(1), 137-151. doi:10.1348/026151003321164672
- Howell, D.C. (2011). *Statistical methods for psychology* (7th ed.). Belmont, CA: Wadsworth Cengage Learning.

- Huang, Y., Chang, M., Chi, Y., & Lai, F. (2014). Health-related quality of life in fathers of children with or without developmental disability: The mediating effect of parental stress. *Quality of life research*, 23(1), 175-183.
- Jenkins, J. M., Simpson, A., Dunn, J., Rasbash, J., & O'Connor T. G. (2005). Mutual influence of marital conflict and children's behavior problems: Shared and non-shared family risks. *Child Development*, 76(1), 24-39. doi:10.1111/j.1467-8624.2005.00827.x
- Jesser, G. H. (2003). Effect of the severity of autism on parental marital satisfaction.

  Unpublished doctoral dissertation. California State University, San Bernardino.
- Johnson, C, Hessl, D., Blasey, C, Eliez, S., Erba, H., Dyer-Friedman, J., Glasser, B., & Reiss, A. (2003). Factors associated with parenting stress in mothers of children with fragile x syndrome. *Journal of Developmental & Behavioral pediatrics*, 24(4), 267-275. doi:10.1097/00004703-200308000-00008
- Kan, M. Y., Sullivan, O., & Gershuny, J. (2011). Gender convergence in domestic work: Discerning the effects of interactional and institutional barriers from large-scale data. Sociology, 45(2), 234–251. doi: 10.1177/0038038510394014
- Karney, B. R. & Bradbury, T. N. (1995). The longitudinal course of marital quality and stability: A review of theory, method and research. *Psychological Bulletin*, *118*(1), 3-34. doi: 10.1037/0033-2909.118.1.3
- Kasari, C, & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders*, 27, 39-57.

- Kau, A.S., Reider, E.E., Payne, L., Meyer, W.A., & Freund, L. (2000). Early behavior signs of psychiatric phenotypes in fragile x syndrome. *American Journal of Mental Retardation*, 105, 286–299. doi:10.1352/0895-8017(2000)105<0286:ebsopp>2.0.co;2
- Kaufmann, W.E., Cortell, R., Kau, A.S., Bukelis, I., Tierney, E., Gray, R.M., et al. (2004). Autism spectrum disorder in fragile X syndrome: communication, social interaction, and specific behaviors. American Journal of Medical Genetics, 129A(3), 225–234. doi: /10.1002/ajmg.a.30229
- Kenrick, D. T., Griskevicius, V., Neuberg, S. L., & Schaller, M. (2010). Renovating the pyramid of needs: Contemporary extensions built upon ancient foundations.
   Perspectives on Psychological Science, 5(1), 292–314.
   doi:10.1177/1745691610369469
- Kerby, D.S., & Dawson, B.L. (1994). Autistic features, personality, and adaptive behavior in males with fragile X syndrome and no autism. *American Journal on Mental Retardation*, 98, 455-462.
- Ki, Y. W., & Joanne, C. C. Y. (2014). Stress and Marital Satisfaction of Parents with Children with Disabilities in Hong Kong. *Psychology*, 5(5), 349-357. doi:10.4236/psych.2014.55045
- Kline, R. (2005). *Principles and practices of structural equation modeling* (2nd ed.). New York, NY: Guilford Press.
- Knapp, J. A. (2005). Raising a child with autism: The impact on the quality of marital relationships. *Dissertation Abstracts International: Section B: The*

- *Sciences and Engineering, 65(10-B), 5407-5411.*
- Komarovsky, M. (1940). The unemployed man and his family: The effect of

  Unemployment upon the man in fifty-nine families. New York: Dryden PR.
- Koos, E. (1946). Families in trouble. New York: King's Crown Press.
- Krauss, M. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation*, 97(4), 393-404.
- Kuhn, J.C., & Carter, A.S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, 76(4), 564-575. doi:10.1037/0002-9432.76.4.564
- Lamb, M. E., Pleck, J. H., Charnov, E. L., & Levine, J. A. (1985). Paternal behavior in humans. *American Zoologist*, 25(3), 883–894. doi:10.1093/icb/25.3.883
- Latson, S. R. (1995). Preventing parent burn out: Model for teaching effective coping strategies to parents of children with disabilities. Learning Disabilities

  Association of America News brief 1-2. Retrieved from http://www.ldanatl.org/aboutld/parents/help/preventing.asp
- Lavee, Y., & Sharlin, S. (1996). The effect of parenting stress on marital quality: A integrated mother-father model. *Journal of Family Issues*, 17(1), 114-136. doi:10.1177/019251396017001007
- Lazarus, R. S., Averill, J. R., & Opton, E. M., Jr. (1974). *The psychology of coping: Issues of research and assessment.* In G. V. Coelho, D. A. Hamburg, & J. E. Adams (Eds.), *Coping and adaptation*. New York: Basic Books.

- Lecavalier, L. L., Leone, S. S., & Wiltz, J. J. (2006). The impact of behavior problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, *50*(3), 172-183. doi:10.1111/j.1365-2788.2005.00732.x
- Lee S, Walker JR, Jakul L, at al., (2004). Does elimination of placebo responders in a placebo run in increase the treatment effect in randomized clinical trials? A meta analytic evaluation. *Depression and Anxiety*, 19(1),10-19. doi:10.1002/da.10134
- Leslie, L. A., Anderson, E. A., & Branson, M. P. (1991). Responsibility for children: The role of gender and employment. *Journal of Family Issues*, 12(2), 197–210. doi:10.1177/019251391012002004
- Levinger, G., & Huston, T. L. (1990). The social psychology of marriage. In F.
- Little, L. (2002). Differences in stress and coping for mothers and fathers of children with Asperger's syndrome and nonverbal learning disorders. *Pediatric Nursing*, 28, 565-570.
- Li-Tsang, C. W., Yau, M. K., & Yuen, H. K. (2001). Success in parenting children with developmental disabilities: Some characteristics, attitudes, and adaptive coping skills. *British Journal of Developmental Disabilities*, 47(93), 61-71. doi:10.1179/096979501799155594
- Long, A. C. J. (2009). Parenting stress and social support in families with children with fragile X syndrome: A comparison of mothers and fathers (Doctoral dissertation).

  Available from ProQuest Dissertations & Theses Full Text database. (UMI No. 3366376).

- Low, C. M. (2013). *Temperament In Young Children With Fragile X Syndrome*(Doctoral dissertation). Available from ProQuest Dissertations & Theses Full

  Text database. (UMI No. 3640048).
- McCarthy A, Cuskelly M, Kraayenoord CE, et al., (2006). Predictors of stress in mothers and fathers of children with fragile X syndrome. *Research in Developmental Disabilities*, 27(6),688-704. doi:10.1016/j.ridd.2005.10.002
- McCubbin, H., Joy, C., Cauble, A., Comeau, J., Patterson, J., & Needle, R. (1980).

  Family stress and coping: A decade review. *Journal of Marriage and the Family*, 42(4), 855-871. doi: 10.2307/351829
- McCubbin, H., & Thompson, A. (Eds.). (1991). Family assessment inventories for research and practice (2nd ed.). Madison, WI: University of Wisconsin.
- McDevitt, S.C., & Carey, W.B. (1978). The measurement of temperament in 3-7 year old children. *Journal of Child Psychology and Psychiatry*, 19(3), 245-253. doi:10.1111/j.1469-7610.1978.tb00467.x
- McKinney, B., & Peterson, B. A. (1987). Predictors of stress of developmentally disabled children. *Journal of Pediatric Psychology*, *12*(1), 133-150. doi:10.1093/jpepsy/12.1.133
- McStay, R. L., Trembath, D., & Dissanayake, C. (2014). Stress and family quality of life in parents of children with autism spectrum disorder: Parent gender and the double ABCX model. *Journal of Autism and Developmental Disorders*, 44(12), 3101-3118. doi:10.1007/s10803-014-2178-7
- Milgram, N. A., & Atzil, M. (1988). Parenting stress in raising autistic children. Journal

- of Autism and Developmental Disorders, 18, 415-424. doi:10.1007/bf02212196
- Moh, T. A. & Magiati, I. (2012). Factors associated with parental distress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders.
   Research in Autism Spectrum Disorders, 6, 293-303.
   doi:10.1016/j.rasd.2011.05.011
- Morris, M. M. (2000). Parental stress and marital satisfaction in families of children with attention deficit/hyper-activity disorder. Unpublished doctoral dissertation.

  University of New Mexico, Albuquerque.
- Muijs, D. (2010). *Doing Quantitative Research in Education with SPSS*. Thousand Oaks, CA: Sage Publications.
- Mullen, S. W. (1997). The impact of child disability on marriage, parenting, and attachment: Relationships in families with a child with cerebral palsy.
- (Doctoral dissertation). Available from ProQuest Dissertations & Theses Full Text database. (UMI No. 9738915).
- Mulson, M., Caldera, Y. M, Pursley, M., Reifman, A., & Huston, A. C. (2002).

  Multilevel factors influencing maternal stress during the first three years. *Journal of Marriage and Family*, 64(4), 944-956. doi:10.1111/j.1741-3737.2002.00944.x
- Myers, B. J., Mackintosh, V. H., Goin-Kochel, R. P. (2009). My greatest joy and my greatest heart ache: Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, *5*(3), 670-684. doi:10.1016/j.rasd.2009.01.004
- Oelofsen, N. (2006). Parental coherence, health, and stress in mothers and fathers of

- pre-school children with developmental disabilities (Doctoral dissertation).

  Available from ProQuest Dissertations & Theses Full Text database.

  (UMI No.U219844).
- Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability*, 31(1), 1-12. doi:10.1080/13668250500349367
- Orloff, A. S. (2009). Gendering the Comparative Analysis of Welfare States: An Unfinished Agenda. *Sociological Theory*, 27(3), 317-343. DOI: 10.1111/j.1467-9558.2009.01350.x
- Otto, H. A. (1963). Criteria for assessing family strength. *Family Process*, 2(2), 329-337. doi:10.1111/j.1545-5300.1963.00329.x
- Patterson, J., & Garwick, A. (1994). The level of meaning in family stress theory. *Family Process*, 33(3), 287-304. doi:10.1111/j.1545-5300.1994.00287.x
- Perry, A. (2004). A model of stress in families of children with developmental disabilities: Clinical and research applications. *Journal on Developmental Disabilities*, 11(1), 1-16.
- Perry-Jenkins, M., Newkirk, K., & Ghunney, A. K. (2013). Family work through time and space: An ecological perspective. *Journal of Family Theory & Review*, *5*(2), 105–123. doi:10.1111/jftr.12011
- Pilisuk, M., & Parks, S. (1983). Social support and family stress. *Marriage and* Family *Review, 6*(1-2), 137-156. doi:10.1300/j002v06n01\_07

- Pisula, E. (2011). Parenting stress in mothers and fathers of children with Autism

  Spectrum Disorders, a comprehensive book on Autism Spectrum Disorders, Dr.

  Mohammad-Reza Mohammadi (Ed.), (pgs. 87-107). InTech, Available from:

  http://www.intechopen.com/books/a-comprehensive-book-on-autismspectrum-disorders/parenting-stress-in-mothers-and-fathers-of-children-with-autism-spectrum-disorders.
- Poop, J. M., Robinson, J. L., Britner, P. A., & Blank, T. O. (2014). Parent adaptation and family functioning in relation to narratives of children with chronic illness. *Journal of Pediatric Nursing*, 29(1), 58-64. doi:10.1016/j.pedn.2013.07.004.
- Ramisch, J. (2010). Marriage and family therapists working with couples who have children with autism. *Journal of Marital and Family Therapy*, *38*, 305-316. doi:10.1111/j.1752-0606.2010.00210.x
- Reyns, T. A. (2006). Relationship of differentiation in marital satisfaction and stress among parents raising a child with autism. *Dissertation Abstracts International*, 66, 7-B. (UMI 3182124).
- Right Diagnosis (2014). *About prevalence and incidence statistics*. Retrieved from http://www.rightdiagnosis.com/admin/preval.htm#rates.
- Rivard, M., & Terroux, A. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(7), 1609-1620.doi:10.1007/s10803-013-2028-z
- Roberts, J.E., Boccia, M., Hatton, D.D., Skinner, M.L., Sideris, J. (2006). Temperament and vagal tone in boys with fragile x syndrome. *Journal of Developmental and*

- Behavioral Pediatrics, 27(3), 193-201. doi:0196-206X/06/2703-0193
- Rodgers, A. Y. (1998). Multiple sources of stress and parenting behavior. *Children and Youth Services Review*, 20(6), 525-546. doi:10.1016/s0190-7409(98)00022-x
- Rodriguez, J. R., Morgan, S. B., & Geffken, G. (1990). Families of autistic children:

  Psychological functioning of mothers. *Journal of Clinical Child Psychology*, 19,

  371-379. doi:10.1207/s15374424jccp1904\_9
- Rodriquez, C, & Murphy, L. E. (1997). Parenting stress and abuse potential in mothers of children with developmental disabilities. *Child Maltreatment*, 2(3),245-251.
- Rogers, M. L., & Hogan, D. P. (2003). Family life with children with disabilities: The key role of rehabilitation. *Journal of Marriage and Family*, 65(4), 818-833. doi:10.1111/j.1741-3737.2003.00818.x
- Rosenthal, R., & Rosnow, R. L. (2008). Essentials of Behavioral Research: Methods and Data Analysis. Boston, MA: McGraw Hill.
- Rothbart, M.K., Ahadi, S.A., Hershey, K.L., Fisher, P. (2001). Investigations of temperament at three to seven years: The children's behavior questionnaire.

  \*\*Journal of Child Development, 72(5), 1394-1408. doi:10.1111/1467-8624.00355\*
- Saloviita, T., Italinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a Double ABCX
- Model. *Journal of Intellectual Disability Research*, *47*(4), 300-312. doi: 10.1046/j.1365-2788.2003.00492.x
- Sander, J. L. & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention.

- Child & Family Behavior Therapy, 19(4),15-32. doi:10.1300/J019v19n04\_02
- Schopler, E., Reichler, R.J., & Renner, B.R. (1986). *The Childhood Autism Rating Scale* (CARS). Los Angeles, CA: Western Psychological Services.
- Schopler, E., & Mesibov, G. B. (1992). *High functioning individuals with*autism. In E. Schopler & G. B. Mesibov (Eds.), *Current Issues in Autism* (pp. 92-103). New York: Plenum.
- Selye, H. (1980). *Selye's guide to stress research* (Vol. 1). New York: Van Nostrand Reinhold.
- Shakhmalian, T. (2005). *How does a child's autism influence parents' marital*satisfaction? An exploratory study. (Doctoral dissertation). Available from ProQuest Dissertations & Theses Full Text database. (UMI No. 3167138).
- Shanahan, M., Roberts, J., Hatton, D., Reznick, J., & Goldsmith, H. (2008). Early temperament and negative reactivity in boys with fragile x syndrome. *Journal of Intellectual Disability Research*, 52(10), 842-854. doi:10.1111/j.1365-2788.2008.01074.x
- Sharpley, C.F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual & Developmental Disability*, 22(1), 19-28. doi:10.1080/13668259700033261
- Sherman, S. L. (2002). Seminars in genetics: Premature ovarian failure in the fragile X 85 syndrome. *American Journal of Medical Genetics*, 97(3), 189-195. doi:10.1002/1096-8628(200023)97:3<189::aid-ajmg1036>3.0.co;2-j

- Shumm, W. A., Nichols, C.W., Schectman, K.L., & Grigsby, C.C. (1983). Characteristics of responses to the Kansas Marital Satisfaction Scale by a sample of 84 married mothers. *Psychological Reports*, *53*(2), 567–572. doi:10.2466/pr0.1983.53.2.567\_
- Skoog, G. R., & Ciecka, J. E. (2010). Measuring years of inactivity, years in retirement, time to retirement, and age at retirement within the Markov model. *Demography*, 47(3), 609-628. doi:10.1353/dem.0.0111
- Stevens, J.P. (2009). Applied multivariate statistics for the social sciences (5th ed.).

  Mahwah, NJ: Routledge Academic.
- Stores, R., Stores, G., Fellows, B., & Buckley, S. (1998). Daytime behaviour problems and maternal stress in children with down's syndrome, their siblings, and nonintellectually disabled and other intellectually disabled peers. *Journal of Intellectual Disability Research*, 42(3), 228-237. doi:10.1046/j.1365-2788.1998.00123.x
- Sullivan. K., Hatton, D., Hammer, J., Sideris, J., Hooper, S., Ornstein, P., et al. (2006).

  ADHD symptoms in children with fragile X syndrome. American Journal of

  Medical Genetics, A, 140, 2275–2288.
- Sullivan, O. (2013). What do we learn about gender by analyzing housework separately From child care? Some considerations from time-use evidence. *Journal of Family Theory & Review*, 5(2), 72–84. doi:10.1111/jftr.12007
- Taanila, A., Kokkonen, J., & Jarvelin, M. R. (1996). The long-term effects of children's early onset disability on marital relationships. *Developmental Medicine and Child Neurology*, 38(7), 567-577. doi:10.1111/j.1469-8749.1996.tb12121.x

- Tassone, F., Hagerman, R.J., Ikle, D.N., Lampe, M., Willemsen, R., Oostra, B.A., & Taylor, A.K. (1999). FMRP expression as a potential indicator for fragile x syndrome. *American Journal of Medical Genetics*, 84(3), 250-261. doi: 10.1002/(sici)1096-8628(19990528)84:3<250::aid-ajmg17>3.0.co;2-4
- Theule, J., Wiener, J., Rogers, M. A., & Marton, I. (2011). Predicting parenting stress in families of children with ADHD: Parent and contextual factors. *Journal of Child and Family Studies*, 20(5), 640-647. doi:10.1007/s10826-010-9439-7
- Tomanik, S., Harris, G., & Hawkins, J. (2004). The relationship between behaviors exhibited by children with autism and maternal stress. *Journal of Intellectual & Developmental Disability*, 29(1), 16-26. doi:10.1080/13668250410001662892
- Turner, M. (1999). Annotation repetitive behaviors in autism: A review of psychological research. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 40(6),839-849. doi: 10.1017/s0021963099004278
- Vetere, E. (1994). Effects of gender, appraisal, coping, and social support on perceived distress in parents of preschoolers with handicaps (Doctoral dissertation, Fordham University, 1994). *Dissertation Abstracts International*, 55 (11-A), 3459.
- Walker, A. (2000). Parenting stress: A comparison of mothers and fathers of disabled and non-disabled children. Unpublished doctoral dissertation, University of North Texas, Denton.
- Waller, W., & Hill, R. (Eds.). (1951). The family: A dynamic interpretation. *Marriage* and Family Living, 14(1), 81-90. doi:10.2307/346722
- Wanamaker, G.M. & Glenwick, D.S. (1998). Stress, coping, and perceptions of child

- behavior in parents of preschoolers with cerebral palsy. *Rehabilitation Psychology*, 43(4), 297-312. doi: 10.1037/0090-5550.43.4.297
- Weber, P. H. (2011). A comparison of parental stress and marital/couple satisfaction as reported by parents raising children diagnosed with pervasive developmental disorder: An online mixed methods study (Doctoral dissertation). Available from ProQuest Dissertations & Theses Full Text database. (UMI No. 3497863).
- Webster, R. I., Majnemer, A., Platt, R. W., Shevell, M. I. (2008). Child health and parental stress in school-age children with a preschool diagnosis of developmental delay. *Journal of Child Neurology*, 23, 1, 32-38. doi:10.1177/0883073807307977
- Webster-Stratton, C. (1988). Mothers' and fathers' perceptions of child deviance: Roles of parent and child behaviors and parent adjustment. *Journal of Consulting and Clinical Psychology*, 56(6), 909-915. doi:10.1037/0022-006x.56.6.909
- Webster-Stratton, C. (1990). Stress: A potential disruptor of parent perceptions and family interactions. *Journal of Clinical Child Psychology*, 19(4),302-312. doi:10.1207/s15374424jccp1904\_2
- White, N., Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17(3), 181–190. doi:10.1111/j.1468-3148.2004.00197.x
- Willoughby, J. C. & Glidden, L. M. (1995). Fathers helping out: Shared child care and Marital satisfaction of parents of children with disabilities. *American Journal on Mental Retardation*, 99(1), 399-406.
- Wolf, L. C, Noh, S., Fisman, S. N., & Speechley, M. (1989). Brief report: Psychological

- effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders*, 19(1),157-166. doi:10.1007/BF02212727
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experiences of parents who have a child with autism. *Qualitative Health*\*Research\*, 18(8), 1075-1083.doi:10.1177/1049732308320112
- Woodman, A. C., Mawdsley, H. P., Hauser-Cram, P. (2015). Parenting stress and child behavior problems within families of children with developmental disabilities:

  Transactional relations across 15 years. *Research in Developmental Disabilities*, 36(1), 264-276. doi:10.1016/j.ridd.2014.10.011

# Appendix A: Demographics Questionnaire (Del Fierro, 2016)

# (Note: All answers are to be inserted using a drop down box via the website)

| 1.         | What is your gender? (Select One)  |
|------------|--|
| 0          | Male   |
| 0          | Female   |
| 0          | Other (please specify)   |
|            |  |
|            |  |
| <i>2</i> . | Do you have a child who has been diagnosed with Fragile X Syndrome by a      |
|            | physician, medical doctor, psychologist or other mental health professional? |
|            | (Select One)   |
| 0          | Yes  |
| 0          | No   |
| 0          | Other (please specify)   |
|            |  |
|            |  |
| 3.         | Has your child who was diagnosed with Fragile X Syndrome lived with you for  |
|            | the past six months? (Select One)  |
| 0          | Yes  |
| 0          | No   |
| 0          | Other (please specify)   |
|            |  |
| _          |  |
|            |  |
| 4.         | What is your child's age who has been diagnosed with Fragile X Syndrome?     |
| 7.         | (Select One)   |
| 0          | 2-12   |
| 0          |  |
|            | Something else (please specify)  |
|            |  |
| _          |  |
| <i>5</i> . | Are you legally married (Select One)   |

| 0          | Yes   |
|------------|---|
| 0          | No  |
| 0          | Other (Specify)   |
|            |   |
|            |   |
| 6.         | What year were you born?                                      |
| 0          |   |
|            |   |
| <i>7</i> . | What is the highest level of education you have completed?    |
|            | (Select One)  |
| 0          | No schooling completed  |
| 0          | Some high school completed, no diploma                        |
| 0          | High school graduate with diploma or the equivalent (e.g. GED |
| 0          | Some college credit or Trade/technical/vocational training    |
| 0          | Associate degree  |
| 0          | Bachelor's degree   |
| 0          | Master's degree   |
| 0          | Professional degree   |
| 0          | Doctorate degree  |
| 0          | Other (please specify)  |
|            |   |
|            |   |
| 8.         | Years married? (Select One)                                   |
| 0          | 1-5 years   |
| 0          | 5-10 years  |
| 0          | 10-15 years   |
| 0          | 15-20 years   |

20-25 years25-30 years30-35 years40+ years

## 9. Household annual income? (Select One)

- o Less than \$25,000
- o \$25,000 to \$34,999
- o \$35,000 to \$49,999
- o \$50,000 to \$74,999
- o \$75,000 to \$99,999
- o \$100,000 to \$124,999
- o \$125,000 to \$149,999
- o \$150,000 or more

# 10. What is your race/ethnicity?

- o White
- o Black or African-American
- o Asian
- o American Indian or Alaska Native
- Other (please specify)

## Appendix B: Permission to Use the Sharing of Childcare Responsibilities Scale and the

#### Parental Stress Level Scale

# Parental Stress Level Scale and Sharing of Childcare Responsibilities Scale

Inbox

X

### (a) Jacqueline Del Fierro <XXX@waldenu.edu>

Feb 29

## to chanchungyan

Hello,

My name is Jacqueline Del Fierro and I am a graduate student conducting research for my dissertation on marital satisfaction, parental stress and sharing of childcare responsibilities.

I am writing with a request to gain permission to utilize the two scales you used in your study: the Stress Level scale, measuring the different sources of stress of parents and the sharing of child care responsibilities scale. These scales were used in your study, *Stress and Marital Satisfaction of Parents with Children with Disabilities in Hong Kong* which was published in 2014.

Would it be possible to also obtain a downloadable copy of these two instruments used in this study?

Thank you in advance for your consideration,

Jacqueline Del Fierro

# (b) Joanne Chan <XXX@gmail.com>

Ма

r 2

#### to me

Hi Jacqueline,

The scales are written in Chinese and you will need to back-translate it. Please let me know if you still want a copy.

Best,

Joanne

## (C) Jacqueline Del Fierro <XXX@waldenu.edu>

Ma

r 2

#### to Joanne

Hello,

I greatly appreciate your quick response.

I would certainly look into having these scales translated.

If you could so kindly forward me a downloadable copy of these two scales: Stress Level scale, measuring the different sources of stress of parents and The Sharing of Child Care Responsibilities scale, I would greatly appreciate it.

Sincerely,

Jacqueline Del Fierro

# (d) Jacqueline Del Fierro <XXX@waldenu.edu>

Ma r 7

#### to Joanne

Hello Joanne.

Hope this email finds you well.

When you get a chance please forward me those two scales and I will look into having them translated.

Scales: Stress Level scale, measuring the different sources of stress of parents and The Sharing of Child Care Responsibilities scale.

I would greatly appreciate it.

Thank you in advance,

Jacqueline Del Fierro

# (e) Joanne Chan <XXX@gmail.com>

Ma r8

#### to me

Hi Jacqueline,

Questions 1-7 are the stress questions and question 8 is about sharing of child care responsibilities.

All the best!

Attachments area

# (f) Jacqueline Del Fierro <XXX@waldenu.edu>

Mar 10

to Joanne

Hello!

Got it, thank you very much! Jacqueline Del Fierro

Appendix C: The Sharing of Childcare Responsibilities Scale and the Parental Stress

Level Scale (Chan Chung Yan, 2014)

(Note: All answers are to be inserted using a drop down box via the website)

The following questions are related to the pressures you face when caring for your child with special needs. Please read all the questions carefully and circle your answer.

(1) Do you feel pressured when accompanying your child to their central training facility (e.g. Early Education Center and Training Center)?
 [Please select. 1 being no pressure and 7 being heavy pressure]

 1 2 3 4 5 6 7

Heavy

Pressure

(2) Do you feel pressured when conducting at home training for your child? [Please select. 1 being no pressure and 7 being heavy pressure]

 1
 2
 3
 4
 5
 6
 7

 No Pressure
 Heavy Pressure

No

Pressure

Pressure

(3) Do you feel pressured when managing the time to care for your child and with completing work and house chores?[Please select. 1 being no pressure and 7 being heavy pressure]

Pressure

1 2 3 4 5 6 7
No Heavy

| (4) Do you feel pressured when guiding the learning of your child with special<br>needs (e.g. Educational needs, placement and programming)?<br>[Please select. 1 being no pressure and 7 being heavy pressure] |  |   |                  |   |   |                                     |  |  |  |  |
|---|--|---|------------------|---|---|-------------------------------------|--|--|--|--|
| 1   | 2  | 3 | 4                | 5 | 6 | 7                                   |  |  |  |  |
| No<br>Pressi  | ıre  |   |                  |   |   | Heavy<br>Pressure                   |  |  |  |  |
| <ul><li>(5) Do you feel pressured when handling the emotions and behaviors of your child with special needs?</li><li>【Please select. 1 being no pressure and 7 being heavy pressure】</li></ul>                  |  |   |                  |   |   |                                     |  |  |  |  |
| 1   | 2  | 3 | 4                | 5 | 6 | 7                                   |  |  |  |  |
| No<br>Pressi  | ıre  |   |                  |   |   | Heavy<br>Pressure                   |  |  |  |  |
| _   | <ul><li>(6) Do you feel pressured by the difference in the development of your child with special needs and other typically developing children of the same age?</li><li>【Please select. 1 being no pressure and 7 being heavy pressure】</li></ul> |   |                  |   |   |                                     |  |  |  |  |
| 1   | 2  | 3 | 4                | 5 | 6 | 7                                   |  |  |  |  |
| No<br>Pressi  | ıre  |   |                  |   |   | Heavy<br>Pressure                   |  |  |  |  |
|   |  |   |                  |   |   | ner in which people view you caring |  |  |  |  |
| I   | _ *  |   | with spect. 1 be |   |   | ure and 7 being heavy pressure      |  |  |  |  |
| 1   | 2  | 3 | 4                | 5 | 6 | 7                                   |  |  |  |  |
| No<br>Pressi  | ıre  |   |                  |   |   | Heavy<br>Pressure                   |  |  |  |  |
| <ul> <li>(8) How much responsibility does your spouse share with you in caring for your child with special needs?</li> <li>【 Please select. 1 being no responsibility and 7 a lot of responsibility】</li> </ul> |  |   |                  |   |   |                                     |  |  |  |  |
| 1   | 2  | 3 | 4                | 5 | 6 | 7                                   |  |  |  |  |
| No<br>Respo   | onsibility   |   |                  |   |   | A lot of<br>Responsibility          |  |  |  |  |

### Appendix D: Permission to Use the Kansas Marital Satisfaction Scale

Title: Establishing Criterion Scores for the Kansas Marital Satisfaction Scale and the Revised Dyadic Adjustment Scale

Author: D. Russell Crane, Kenneth C. Middleton, Roy A. Bean

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# Appendix E: Kansas Marital Satisfaction Scale (Schumm et al., 1983)

# (Note: All answers are to be inserted using a drop down box via the website)

| Item  | Extremely<br>Dissatisfied | Very<br>Dissatisfied | Somewhat<br>Dissatisfied | Mixed | Somewhat<br>Satisfied | Very<br>Satisfied | Extremely Satisfied |
|---|---------------------------|----------------------|--------------------------|-------|-----------------------|-------------------|---------------------|
| 1. How satisfied you with your husband (or wife a spouse?               |                           | 2                    | 3                        | 4     | 5                     | 6                 | 7                   |
| 2. How satisfied you with your marriage?                                | 1<br>are                  | 2                    | 3                        | 4     | 5                     | 6                 | 7                   |
| 3. How satisfied you with your relationship with your husband (o wife)? | n                         | 2                    | 3                        | 4     | 5                     | 6                 | 7                   |

wife)?

#### Appendix F: Participant Invitation

## Stress and marital satisfaction of parents with children with Fragile X Syndrome

Jacqueline Del Fierro, a Ph.D. clinical doctoral student at Walden University (under the advisory of Dr. Jesus Tanguma), is conducting a study about parent's stress and marital satisfaction experience with children with Fragile X Syndrome due to their shared child care responsibilities.

### Parents who are eligible to participate must meet the following requirements:

- Be legally married
- Have at least one child diagnosed with Fragile X Syndrome by a physician, medical doctor, psychologist or other mental health professional between the ages of 2-12.
- Have the child who was diagnosed with Fragile X Syndrome between the ages of 2-12 lived with them for at least 6 months.
- Have the ability to understand and read English well enough to independently participate in this study.

You are invited to complete the study online at www.fxsparents.com. The study will take approximately 15-20 minutes to complete. No compensation is offered for participation. Your participation is strictly voluntary and confidential.

If you are interested in learning more about this study, please contact the researcher, Jacqueline Del Fierro at: XXX@waldneu.edu