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Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

David F. Kropff

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Walden University
2021

Abstract

Stress, Coping, Social Support, and Marriage Satisfaction in Parents of Children with Congenital Heart Defects

by

David F. Kropff

MS, Walden University, 2011

BS, Binghamton University, 2007

Proposal Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Counseling Psychology

Walden University

May 2021

Abstract

Congenital Heart Defects (CHDs) are the most common type of birth defect in the United States. Children diagnosed with CHD require specialized intervention and a myriad of additional supports resulting in higher levels of stress for their parents. The purpose of this study was to analyze the impact of parental stress (parental distress, parent-child dysfunctional interaction, difficult child, and total parental stress), parental support (spouse/parenting partner relationship), and parental coping (maintaining social support, maintaining family integration, and understanding the healthcare situation) on marriage satisfaction among parents with children who have a CHD. Minuchin's structural family theory was used to guide this research, as it focuses upon the relationship between stress and levels of emotional functioning within a familial dynamic. Standard multiple regression, with a convenience sample of 206 parents from CHD support/advocacy groups, was used to identify potential variables that predict marriage satisfaction. The results of this study indicated that parent/child dysfunctional interaction was a significant predictor of the marital satisfaction subscale and total marriage satisfaction. The variables of difficult child and maintaining social support were both significant predictors of idealistic distortion. Spouse/parenting partner relationship was a statistically significant predictor of all measures of marriage satisfaction. All other included subscales were not significant predictors for any of the measures of marriage satisfaction. These findings have positive social change implications, as understanding how parental stress, support, and coping predicts marriage satisfaction differently will allow for more appropriately focused interventions, support, and counseling for parents of children with CHDs.

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Dedication

I dedicate this dissertation to my two beautiful sons, Caleb and Cole. Let this small accomplishment of mine be an example to both of you that anything is possible as long as you work hard and persevere. You two motivate and inspire me every day of my life. Cole, never stop exploring and learning new things. Caleb, you are whole-hearted and the bravest heart warrior I have ever met. Daddy loves you both so much.

Acknowledgments

I would like to express unimaginable amounts of gratitude to everyone in both my professional and personal life who have helped me achieve this goal. Thank you to my parents, sister, extended family, and my lifelong friends for all the words of encouragement and motivation. Additionally, I would like to thank my chair, Dr. Anthony Perry, for his guidance, expertise, and patience with me throughout this process. Above all, thank you to my amazing wife, Jennifer, whose unwavering support and faith in me has meant more than I can ever express.

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Chapter 1: Introduction to the Study

The focus of this research was to identify if parental stress, parental support, and parental coping were predictors of marriage satisfaction for parents of children with Congenital Heart Defects. Currently, Congenital Heart Defects (CHDs) are the most common type of birth defect in the United States (Centers for Disease Control and Prevention, 2016). CHDs represent a unique and challenging burden for parents to face when raising a child and they are 60 times more prevalent than any type of childhood cancer. Children diagnosed with CHD frequently require specialized care, surgical intervention, and a myriad of additional supports. For the parents of children with CHD, caring for their child has led to higher perceived levels of stress as compared to the parents of children who do not have CHD (Rassart, 2013).

Despite research that links parental stress and marriage satisfaction, a gap existed in current research pertaining to the impact parental stress has on the marriage satisfaction of parents with children with CHD. Also, studies had not yet examined the role that parental coping plays in either bolstering or reducing the marriage satisfaction of parents with children with CHDs. To address these gaps, I explored how varying components of parental stress, parental support, and parental coping predicted marriage satisfaction among parents of children with CHD. Understanding how parental stress and coping predicts marriage satisfaction within this population could allow for more appropriately focused interventions, support, and counseling for parents of children with CHD.

Background

Congenital heart defects are the most prominent and significant health issue currently facing children in the United States. The incidence of CHD is approximately 8-10 per 100 live births (Gilboa et al., 2016). As of 2010, it is estimated that approximately 2.4 million individuals (1.4 million adults and 1 million children) were living with CHDs in the United States (Gilboa et al., 2016). These numbers were supported by another study, which found that there are approximately 1.35 million infants with CHD born every year worldwide (Van der Linde et al., 2011). The various types of CHD are generally categorized by severity and by type of surgical intervention needed. The prognosis for children with CHD also varies on an individualized basis. Depending upon the CHD severity, a child will then either be given a regimen of medications (in mild cases), be given a corrective procedure via cardiac catheterization, undergo open-heart surgery, or receive a heart transplant (Ailes et al., 2015). The mortality rate for children with CHD is greatest during the first year of life.

Raising a child with complex medical needs, such as CHD, can often lead to stress (Soulvie et al, 2012). Abidin (1995) defined parenting stress as the stress that a parent experiences related to their child's characteristics and experiences in their parenting role. Past research has indicated that parents of children with physical disabilities perceive more parental stress than parents of children who do not have physical disabilities (Feizi et al., 2014; Pipp-Siegel et al., 2002). Miodrag et al. (2015) found that perceived levels of stress amongst parents of chronically ill children arose due to fear/uncertainty about their future health. Diagnoses such as ADHD and anxiety have

increasingly been seen within children with CHD (Demaso et al., 2017). Such neurocognitive deficits that can impact cognitive functioning occur as a side effect of surgical bypass, which restricts oxygen to the brain during corrective procedures (Sterken et al., 2016). It is for these reasons that longitudinal studies evaluating the long-term symptoms of depression and anxiety among parents of children with CHD have found significantly elevated levels of anxiety and depression (Solberg et al., 2011).

These parental stress reactions can be impacted, positively or negatively, by an individual's ability to cope. Rychik et al. (2013) found that higher levels of acceptance of CHD were associated with decreased amounts of depression and anxiety symptoms. Whiting (2014) asserted that when parents discover a complex health concern in their children, their ability to cope depends on how they search for external sources of care and how they perceive that care and support is provided. Acknowledging the importance of social support and increasing public awareness appeared important for proper parental coping and minimizing parental stress (Bratt et al., 2015).

Stress can have a substantial impact on marital satisfaction (e.g., Randall & Bodenmann, 2017). For couples raising a child with any kind of disability, marriage/relationship satisfaction can be negatively affected compared to the broader population (Hatton et al., 2010). Rychik et al. (2013) asserted that a sample population of parents of children with CHD identified in utero reported lower overall marriage satisfaction as compared to a sample of parents whose infants were not diagnosed with CHD in utero. These same partners of infants with CHD also reported significantly higher levels of anxiety and stress symptoms. These studies suggest that a diagnosis of

CHD or other disability can potentially create conflict within couples due to increased stress.

Problem Statement

For the parents of children with CHD, previous research has established that caring for their child has led to higher perceived levels of stress as compared to the parents of children who do not have CHD (Rassart, 2013). Studies have also found that uncertain future health and comorbid child behavior challenges were factors that added to perceived stress of parents raising a child with a CHD (Nadeem et al., 2016; Soulvie et al., 2012).

Additionally, research has asserted that high stress levels within a couples' relationship can negatively influence marriage satisfaction (Randall & Bodenmann, 2017). However, current research had not addressed the influence that parental stress might have on the marriage satisfaction of parents with children with CHD. Also, parental coping and its role in parental stress and marriage satisfaction amongst parents with children with CHD had not been researched in-depth. These gaps were significant, as CHD parents possess a uniquely stressful relationship dynamic different than their counterparts with children without CHD (Hearps et al., 2014). This research sought to increase the understanding of how an individual's ability to cope with stress affects their marriage satisfaction within this specific population. Previous research has asserted that CHD parents currently lack adequate and available coping strategies and counseling services (Leon et al., 2013). Research has shown that increasing the availability of counseling services to parents, regardless of circumstance, subsequently aids in

increasing coping skills, communication, and confidence (Ahn et al., 2014). Therefore, understanding how these individuals deal with parental stress and cope with their children's illness may lead to an understanding as to their perceptions of marriage satisfaction or dissatisfaction.

Purpose of the Study

The purpose of this study was to analyze the relationship between parental stress, parental support, parental coping, and marriage satisfaction among parents with children with CHD. Specific components of parental stress (parental distress, parent-child dysfunctional interaction, difficult child, total parental stress), parental support (spouse/parenting partner relationship), and parental coping (maintaining family integration, cooperation, and an optimistic definition of the situation, maintaining social support, self-esteem, and psychological stability, understanding the medical situation through communication with other parents and consultation with medical staff) served as the independent variables (potential predictors). Three components of marriage satisfaction (idealistic distortion, marital satisfaction, and total marriage satisfaction) served as the dependent variables (outcome variables). Understanding how parental stress and coping predicts marriage satisfaction differently will allow for more appropriately focused interventions, support, and counseling for parents of children with CHD.

Research Questions and Hypotheses

The following were the research questions and hypotheses for this study:

Research Question 1: To what extent does the parental distress component of parental stress, as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$1: Parental distress is not a significant predictor of marriage satisfaction.

H_a1: Parental distress is a significant predictor of marriage satisfaction.

Research Question 2: To what extent does the parent-child dysfunctional interaction component of parental stress, as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$2: Parent-child dysfunctional interaction is not a significant predictor of marriage satisfaction.

H_a2: Parent-child dysfunctional interaction is a significant predictor of marriage satisfaction.

Research Question 3: To what extent does the difficult child component of parental stress (i.e., how challenging the parent perceives the child to be), as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$3: Difficult child is not a significant predictor of marriage satisfaction.

H_a3: Difficult child is a significant predictor of marriage satisfaction.

Research Question 4: To what extent does the parental stress total score, as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$4 Parental stress is not a significant predictor of marriage satisfaction.

H_a4: Parental stress is a significant predictor of marriage satisfaction.

Research Question 5: To what extent does the spouse/parenting partner relationship component of parental support, as measured by the Parenting Stress Index-4 Long Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$5: Spouse/parenting partner relationship is not a significant predictor of marriage satisfaction.

H_a5: Spouse/parenting partner relationship is a significant predictor of marriage satisfaction.

Research Question 6: To what extent does the maintaining family integration, cooperation, and an optimistic definition of the situation component of parental coping, as measured by the Coping Health Inventory for Parents, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$6: Maintaining family integration, cooperation, and an optimistic definition is not a significant predictor of marriage satisfaction.

H_a6: Maintaining family integration, cooperation, and an optimistic definition is a significant predictor of marriage satisfaction.

Research Question 7: To what extent does the maintaining social support, self-esteem, and psychological stability component of parental coping, as measured by the Coping Health Inventory for Parents, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$7: Maintaining social support, self-esteem, and psychological stability is not a significant predictor of marriage satisfaction.

H_a7: Maintaining social support, self-esteem, and psychological stability is a significant predictor of marriage satisfaction.

Research Question 8: To what extent does the understanding the medical situation through communication with other parents and consultation with medical staff component of parental coping, as measured by the Coping Health Inventory for Parents, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$8: Understanding the medical situation through communication with other parents and consultation with medical staff is not a significant predictor of marriage satisfaction.

H_a8: Understanding the medical situation through communication with other parents and consultation with medical staff is a significant predictor of marriage satisfaction.

Theoretical Framework

The theoretical foundation that guided this research was Minuchin's (1974) structural family theory. Structural family theory was developed by Minuchin as a way to theorize how an individual's challenges can contribute to a dysfunctional family system. By examining the interactions of family members, structural family theory seeks to identify patterns and works to redefine relationships among members of that family (Minuchin, 1974).

Minuchin asserted that stress also arises around idiosyncratic problems with a family (Pardeck, 1989). Specifically, structural family theory contends that dysfunctional transactional patterns may appear around idiosyncratic issues unique to a given family such as a family with a handicapped child. When a child with a handicap or disability is young, parents are able to adapt to a child's needs. However, as a child ages and begins interacting with social systems outside the family, he or she may not be able to adapt effectively. This inability to adapt may overload the family system, leading to parental stress and dysfunction (Postkammer & Nickolai, 1985). Similarly, structural family theory states that caring for an ill family member causes a redistribution of responsibility within the family dynamic. This requires parents to adapt and adjust the entire family system.

Structural family theory views the family dynamic as a social group that influences and is influenced by social contexts (Minuchin, 1974). These social contexts can be either internal or external. For example, both one's internal perceptions of failure and the external loss of a job can unbalance the family dynamic (Vetere, 2001). Similarly, structural family theory asserts that the family dynamic can influence the emotions of its members. An example of this is children having symptoms of anxiety as a response to the stressors placed upon their parents (Minuchin, 1974). According to Minuchin (1974), stress and maladaptive behavior develop in the family when it cannot adapt to these internal or external burdens. This relationship between burden and stress has also been shown to impact levels of family functioning (Mitrani et al., 2006).

Minuchin's structural family theory has been applied to previous research focused on stress and the health of the family. Vetere (2001) contended that structural family theory could be applied to stress and conflict in couples, childhood behavior challenges, and chronic physical illness in children. Regarding chronic childhood illness, Minuchin (1974) contended that the family is a system. As part of that system, interpersonal patterns within a family interact with individual biological functioning, including illnesses. Since an individual's functioning can be impacted by interpersonal patterns of interaction, Minuchin's structural family theory is applicable to both stress and conflict in couples when raising a chronically ill child.

Similarly, structural family theory has also been used to highlight the caregiver stress process when caring for chronically sick family members (Mitrani et al., 2006). The levels of stress among caregivers have been shown to directly impact family

functioning, satisfaction, and general well-being (Mitrani et al., 2006). Structural family theory relates to the current study because it identifies how dysfunction in the family dynamic arises due to internal or external burdens (Minuchin, 1974). The stressful burden of raising a chronically ill child with CHD can impact family functioning. When the perceived roles and subsystems of the family are disrupted by a CHD diagnosis, Minuchin's explanation of the emergence of a dysfunctional family system could explain why levels of coping and marriage satisfaction become affected.

Nature of the Study

The nature of the study was a quantitative, nonexperimental correlational design. A correlational design allowed me to explore the relationship between these variables and gather data in a natural setting (Frankfort-Nachmias & Nachmias, 2008). A correlational design is a common and appropriate design for quantitative studies using multiple regression. This design was suitable for my research questions, as my goal was to find correlations and relationships between chosen variables. Furthermore, a correlational design is the most commonly used within survey research. Since my study collected data from one specific population at one time, it was the most appropriate (Frankfort-Nachmias & Nachmias, 2008). While mostly observational in nature, correlational designs can garner information on relationships between several variables (Stangor, 2011). Correlational designs often utilize surveys and a larger number of participants.

Specific components of parental stress (parental distress, parent-child dysfunctional interaction, difficult child, total parental stress), parental support (spouse/parenting partner relationship), and parental coping (maintaining family

integration, cooperation, and an optimistic definition of the situation, maintaining social support, self-esteem, and psychological stability, understanding the medical situation through communication with other parents and consultation with medical staff) served as the independent variables (potential predictors). Three components of marital satisfaction (idealistic distortion, marital satisfaction, and total marriage satisfaction) served as the dependent variables (outcome variables).

The target population consisted of parents of children with congenital heart defects from the United States who were married at the time of the survey. I recruited participants from both the Long Island, New York area, as well as online via support/advocacy groups. The parents must have had a child with a congenital heart defect that had been diagnosed by a medical professional. Data was collected from participants via online survey. Data relevant to parental stress was acquired via the Parenting Stress Index-4 Short Form (Abidin, 1990b). Data relevant to parental support was acquired via the Parenting Stress Index-4 Long Form (Abidin, 1990a). Data relevant to parental coping was acquired via the Coping Health Inventory for Parents (McCubbin et al., 1983). Data relevant to marriage satisfaction was acquired via the ENRICH Marital Satisfaction Scale (Fowers and Olson, 1993). These surveys were conducted via SurveyMonkey, and data was analyzed using SPSS software.

Definitions

Congenital Heart Defects (CHDs): A malformation of the heart, aorta, or other large blood vessels that is the most frequent form of major birth defect in newborns (Gilboa et al., 2016).

Parental Stress: The stress that a parent experiences that is directly related to child characteristics, parent characteristics, and experiences that are related to the parenting role (Abidin, 1995).

Coping: A person's constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources (Lazarus & Folkman, 1984)

Parental Coping: Both the cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing when raising a child (Ahn, Lee, & Choi, 2014).

Marriage Satisfaction: The favorableness of attitude towards one's own marriage (Arrindell, Boelens, & Lambert, 1983).

Assumptions

Assumptions were made for this study in order to determine potential outcomes and minimize threats to validity. These assumptions were believed to be possible based upon the population and methodology of this research study. There were several assumptions that were pertinent to this study. Since surveys are measures of self-report that may lend themselves to false reporting, I assumed that all participants would answer these survey questions honestly. Included within the survey was a statement that asked all respondents to answer all questions as truthfully as possible. As part of my established consent form, it was assumed that all participating in this study had a sincere desire to do so, and that accurate responses would be collected. Similarly, I assumed that a parent would report accurate responses concerning their children and their feelings pertaining to

them. Additionally, I assumed that all respondents to these surveys carefully read and understood the items as they are written and that all answers would reflect what the item intended to measure. With human error, it is possible that participants could have misread or mistaken the wording of questions or answers, which might have inaccurately portrayed results.

Regarding the surveys being used, another assumption for this study was that all participants could read and appropriately respond to English, as the surveys were only available in English. Understanding the survey questions was crucial to participant responses. Finally, I assumed that the surveys included within this study accurately measured the constructs as expected.

Scope and Delimitations

The scope of this study covered marriage satisfaction amongst parents of children with CHD. The study examined how measures of parental stress, parental support, and parental coping predict marriage satisfaction within this population. In order to address how these variables predict marriage satisfaction amongst parents of children with CHDs, it was first necessary to examine how parental stress arises when raising a chronically ill child. A myriad of studies assert this, as parents raising a child without CHD consistently report less parenting stress than parents raising a chronically ill child (Popp et al., 2014; Rassart, 2013). Specific studies examining the parental stress of raising a child with CHD mirror these same findings (Darling et al., 2012; Rychik et al., 2013). Parental coping has been asserted as a variable that can either exacerbate or aid in symptoms of parental stress (Leon et al., 2013). For parents raising a child with CHD, the ability to cope

effectively with diagnosis and treatment can directly impact perceptions of parental stress levels (Whiting, 2014).

Stress can have a substantial impact on marital satisfaction. Everyday stressors can influence relationship functioning, even without the presence of a chronically ill child (Randall & Bodenmann, 2017). These stressors (financial constraints, social life, medical concerns) are not necessarily the same as those brought about by raising a child with CHD. Due to the broad nature of previous research involving parental stress, coping, and marriage satisfaction as separate entities, the scope of this study was narrowed to those parents raising a child with CHD. The nature of the selected surveys attempted to uncover how, within this specific population, parental stress and parental coping predict marriage satisfaction. There are many variables related to stress, coping, and marriage satisfaction. Stress can arise from a variety of sources.

Several delimitations became apparent within this research study. I recruited participants from online support groups and online CHD organizations. I anticipated that most of the participants would come from these groups. Therefore, this study may not have been representative of individuals in a broader CHD community who may not utilize these doctors or support outlets. For example, the accumulated data may not reflect the responses of CHD parents that do not affiliate with a support group. One additional delimitation involved potential use of the Walden participant pool. However, the Walden participant pool was not used, as no participants in this pool met the criteria for this study. Other delimitations of this research are that participants needed to be English-speaking, and they must have been at least 18 years of age. Also, they must have

been able to read at a high school reading level, because the involved survey was written at that educational level. This might have limited the scope of viable participants and restricted my access to a portion of the population. Since respondents must also have been married and the biological parents of a child with a CHD, it also placed boundaries on other caregivers/guardians responding. Similarly, parents who were divorced/currently living together or had not had custody or guardianship for at least 2 years were excluded. In addition, since I have stipulated that the child must have a CHD that has been officially diagnosed, this provided a delineation between children with a diagnosis, and others with presumptive health concerns. Parents who did not have children who met these criteria were not included in this study. This study could potentially have generalizability to future research. Better understanding of the stress, coping, and marriage satisfaction of CHD parents could lead to an enhanced understanding of the stressors facing parents of children with other chronic diseases or illnesses.

Limitations

Because convenience sampling was utilized for this study, participants were not obtained by random sampling. Since it is not a random sample, the study's results may have limits on generalizability to the larger population (Frankfort-Nachmias & Nachmias, 2008). However, by collecting data from a wider range of support groups and local CHD organizations, I attempted to enhance generalizability. Furthermore, use of a multiple regression analysis model typically allows for the identification of relationships between the independent variables and dependent variable to make predictions. As a result,

multiple regression analysis does not identify causation. Results from this study were also limited by the reliability and validity of the scales and surveys used.

The participants' responses to survey questions may also have been a limitation of this study if they responded to questions in a manner that benefits them. Such response bias could arise if they either did not report accurate information or if they responded deceptively for whatever reason. Participants may engage in social desirability bias when they realize what the study is about (Schaeffer et al., 1991). Also, asking parents of children with CHD to respond honestly about their levels of stress may have led to higher rates of dropout if they became uncomfortable during the survey process. If parents with less parenting stress became more likely to complete the scales and submit them, and more respondents with higher parental stress dropped out, the resulting marriage satisfaction data would not be representative of the true population of parents. Also, if parents experiencing high rates of stress perceived either time and/or financial constraints in their daily life, they might have been less likely to participate in these surveys. This could also have potentially skewed results. There will always be other factors that contribute to marriage satisfaction or dissatisfaction that are independent of raising a child with CHD. Similarly, since there are many different variables that can impact both parenting stress and marriage satisfaction, the surveys might have reflected stress and/or marriage satisfaction responses that arose from other areas of an individual's life other than having a child with CHD. Another potential limitation to research might have been the severity of a child's CHD. CHD severity can impact a wide range of treatment options, prognosis, and long-term care for both the child and caring family (Ailes et al.,

2015). Because this study did not directly ask each participant to rate the severity of their child's CHD, the results might not have conveyed the relationships between CHD severity, stress, coping, and marriage satisfaction.

Significance

This study fills a gap in the literature by examining which factors of parental stress, parental support, and parental coping predict marriage satisfaction amongst parents raising a child with CHD. The relationship of these factors had not been researched regarding parents of children with CHD. This gap was significant, as CHD can place parents at a higher risk of psychological dysfunction than parents of children without CHD (Hearps et al., 2014). Although previous research had examined parental stress and its role in raising a child with a CHD, it had not examined how this parental stress impacts marital satisfaction (Nadeem et al., 2016). Furthermore, research had yet to address the factor of parental coping, and how it impacts marriage satisfaction among parents of children with CHD. With increased knowledge in this specific area, improvements can be made in the areas of counseling services, support groups, and parental education resources (Ahn et al., 2014). Moreover, an increase in service availability can lead to alleviation of parental stress, and, therefore, increased marital satisfaction (Rychik et al., 2013). The results from this study can have practical applications in understanding the impact of parental stress among these parents. This study can result in positive social change by increasing awareness of the stress that raising a child with a CHD has on marriage satisfaction, as well as how certain parental

coping strategies can mitigate the negative effects of stress related to raising a child with CHD.

Summary

Congenital Heart Defects (CHDs) are the most common type of birth defect in the United States (Gilboa et al., 2016). For the parents of children with CHD, caring for their child has led to higher perceived levels of stress as compared to the parents of children without CHD (Rassart, 2013). The purpose of this study was to analyze the impact of parental stress, parental support, and parental coping on marriage satisfaction among parents with children with CHDs. This study has addressed a gap in literature by examining parents of children with CHD and how parental stress, support, and coping affect marital satisfaction. Understanding how parental stress and coping predicts marriage satisfaction differently allows for more appropriately focused interventions, support, and counseling for parents of children with CHD.

In this chapter, I have provided background information pertaining to parental stress, coping, and marriage satisfaction. I have also identified the purpose of this research and the problem statement. Chapter 1 also described the identified research questions of this study, as well as the theoretical framework of Minuchin's structural family theory. Assumptions for this study were also identified, in addition to its potential limitations. Further, the study's scope and delimitations were addressed. This chapter concluded by addressing the significance of this study and its implications for potential positive social change.

Chapter 2 includes a description of the literature search strategy followed by a more detailed discussion of the identified theoretical frameworks. The chapter also includes a background section on congenital heart defects, a comprehensive review of the literature that addresses parental stress across various scopes of child health, a review of parental coping literature, and a review of studies pertaining to marriage satisfaction.

Chapter 2: Literature Review

Congenital heart defects (CHDs) are the most common type of birth defect in the United States, affecting nearly 40,000 live births per year (Centers for Disease Control and Prevention, 2016). Children diagnosed with CHD often require specialized care, surgical intervention, and a myriad of additional supports. For the parents of children with CHD, previous research has established that caring for their child is associated with higher perceived levels of stress as compared to the parents of children without CHD (Rassart, 2013). Studies exploring the sources of stress for parents of children with CHD have found that uncertain future health, additional financial burdens, and comorbid child behavior challenges added to perceived parental stress (Nadeem, et al., 2016; Soulvie et al., 2012). Positive coping skills have also been associated with mitigating parental stress when caring for sick children (Bratt et al., 2015). Additionally, research has found that higher levels of stress within any couples' relationship can negatively impact overall marriage satisfaction (Randall & Bodenmann, 2017).

Current research had not addressed the independent impacts of stress, support, and coping on marriage satisfaction among parents of children with CHD. This gap is significant, as CHD can place parents at a higher risk of psychosocial dysfunction than their counterparts (Hearps et al., 2014).

In this chapter, I provide a review of the impact that raising a child with a CHD has on parenting stress. In addition, I examine parental coping when raising a child with health issues. Further, research on marriage satisfaction when raising a chronically ill child is discussed. The present study sought to address the impact that parental stress,

support, and coping have on the marriage satisfaction of parents with children with CHDs.

The literature review also outlines the theoretical foundation that guided this research. I provide a brief background into CHD, which includes the symptoms of CHD, prognosis, incidence, and prevalence. The literature review then addresses how raising a child with differing disabilities compares to raising a child with CHD. Included among these diagnoses are developmental disabilities, chronic illnesses, and physical disabilities. In this review, I will also discuss how effective versus ineffective parental coping strategies can affect levels of perceived parental stress. Additionally, the impact that raising a sick child has on marriage satisfaction is examined. Research examining various external and internal familial stressors is also reviewed for their impact on marriage satisfaction.

Literature Search Strategy

In conducting this review of the literature, I used Walden University Library's database system, retrieving articles from PsychINFO, PsychArticles, EBSCOhost Online Research Databases, Academic Research Complete, and Medline. In addition, I used Google Scholar to search for additional articles that I was not able to identify through the aforementioned databases. The key search terms and phrases used to search these databases included the following: *congenital heart defects, congenital heart disease, CHD, parental stress, stress, children, perceived stress, marital satisfaction, marriage satisfaction, relationship satisfaction, relationship stress, child health, children with CHD, coping, parental coping, disabled children, sick children, parenting satisfaction,*

and *CHD education*. These terms were searched individually, as well as in combination, such as *marriage satisfaction* and *congenital heart disease.* The majority of studies were less than 4 years old. However, some older cross-referenced material that was deemed relevant to this research study was also included. Both primary and secondary sources, such as literature reviews and research studies were utilized for this literature review.

Theoretical Framework

The theoretical foundation that guided this research was Minuchin's (1974) structural family theory. Structural family theory was established by Salvador Minuchin as a manner of conceptualizing how someone's problems can disturb the greater family system. According to Minuchin, the family structure is defined by the recognized rules and individual roles that guide the family. These systems that are developed establish boundaries for the family and lead to advanced patterns for interpersonal interaction and communication (Minuchin, 1974).

Structural family theory views the family component as a social group that both influences and is influenced by social contexts/cues (Minuchin, 1974). These social contexts are both internal and external. Since structural family theory contends that the family dynamic can influence the emotions of its members, it may see children having symptoms of anxiety as a response to the stressors placed upon their parents (Minuchin, 1974). Stress and maladaptive behavior develop when a family cannot adapt to these internal or external burdens (Minuchin,1974). This relationship between burden and stress also impacts levels of family functioning (Mitrani et al., 2006). Minuchin asserted that stress also arises around idiosyncratic problems with a family (Pardeck, 1989).

Specifically, structural family theory contends that dysfunctional transactional patterns may appear around idiosyncratic issues unique to a given family such as a family with a handicapped child. When a child with a handicap or disability is young, parents are able to adapt to a child's needs. However, as a child ages and begins interacting with social systems outside the family, he or she may not be able to adapt effectively. This inability to adapt may overload the family system, leading to parental stress and dysfunction (Postkammer & Nickolai, 1985). Similarly, structural family theory states that caring for an ill family member causes a redistribution of responsibility within the family dynamic. This requires parents to adapt and adjust the entire family system.

Minuchin's structural family theory has previously been applied to research focused on stress and the health of the family. Vetere (2001) stated that structural family theory could be applied to childhood behavior challenges, stress and conflict in couples, and chronic physical illness in children. Regarding chronic childhood illness, Minuchin (1974) stated that the family is a system. As part of that system, interpersonal patterns within a family structure interact with individual biological functioning, including illness. Therefore, since one's functioning can be impacted by interpersonal patterns of interaction, Minuchin's structural family theory can be applied to stress and conflict in couples when raising a chronically ill child.

The level of caregiver stress has been shown to directly impact family functioning, satisfaction, and general well-being (Mitrani et al., 2006). Structural family theory has also highlighted the caregiver stress process when caring for chronically sick family members (Mitrani et al., 2006). The viewpoints of structural family theory related

to the current study because they identified how dysfunction in the family system arises due to internal or external problems (Minuchin, 1974). The encumbrance of raising a chronically ill child with CHD can impact family and marital functioning. When the perceived marital roles of the family are disturbed by a CHD diagnosis, Minuchin's description of the emergence of a dysfunctional family system could clarify why levels of coping and marriage satisfaction become affected.

Congenital Heart Defects

Congenital heart defects are the most prevalent and significant health issue currently facing children in the United States. Presently, the incidence of CHD is approximately 8-10 per 100 live births (Gilboa et al., 2016). This was an increase in incidence from 4-8 per 100 live births measured between 1985 and 2000 (Marelli et al., 2007). As of 2010, it is estimated that approximately 2.4 million individuals (1.4 million adults and 1 million children) were living with CHDs in the United States (Gilboa et al., 2016). These numbers were supported by another study, which asserted that there are approximately 1.35 million newborns with CHD every year (Van der Linde et al., 2011).

The various types of CHDs are generally categorized by severity and by type of surgical intervention needed. Those diagnoses categorized as Block 1 are typically regarded are severe, as they usually necessitate immediate surgical intervention after birth to save life (Van der Linde et al., 2011). Among these diagnoses are univentrical heart, tetralogy of fallot, transposition complex, hypoplastic left heart syndrome, truncus arteriosus, and atrioventricular canal defect (Marelli et al., 2007). All other CHDs are typically categorized as less severe as compared to these six.

The symptoms of CHD can vary widely. However, severe CHDs are typically denoted by pale gray or blue skin color (cyanosis), rapid breathing, swelling in the legs, abdomen or eyes, shortness of breath, and poor weight gain (Wren et al., 1999). The treatment of CHD is determined by its severity. Currently, most severe CHDs are recognized by medical professionals when a baby is still in utero. A fetal echocardiogram allows a doctor to view the comprehensive anatomy of a child's heart prior to their birth (Rychik et al., 2013). After a fetal echocardiogram, the rest of the child's development and delivery are carefully monitored by a treatment team. Immediately after birth, the child is given a cardiac MRI, pulse oximetry to measure oxygenated blood flow, and cardiac catheterization to plan treatment procedures **(**Arya et al., 2013).

Depending upon the CHDs severity, a child will then either be given a regimen of medications (in mild cases), be given a corrective procedure via cardiac catheterization, undergo open-heart surgery, or receive a heart transplant (Ailes et al., 2015). After these surgical interventions, CHD children require lifelong medical monitoring and treatment. These involve continual follow-up with pediatric cardiology, restrictions on exercise, and increased infection preventions (Wren et al., 1999). Typically, as CHD children age, the need becomes greater for additional procedures to deal with the strain placed upon the heart by the child's growing body.

The prognosis for children with CHD also varies on an individualized basis. The mortality rate for children with CHD is greatest during the first year of life (Best & Rankin, 2016). Research has concluded that mild cases of CHD (such as diagnoses of atrial septal defect and ventricular septal defect) have the highest survival rates beyond

age 10, while severe cases of CHD (such as Hypoplastic left heart) have the lowest (Best & Rankin, 2016; Sarajuuri et al., 2012). Best and Rankin (2016) found that 87.0% of children born with CHD survived to age 1 year, 85.4% survived to age 5 years, and 81.4% survived to age 10 years (Best & Rankin, 2016). There is limited research that reports survival rates beyond age 10 years, but survival appears to gradually decrease into adulthood (Ailes et al., 2015). Additionally, with many severe cases of CHD, the surgical interventions conducted during infancy place a strain on other anatomical structures, such as the liver and lungs (Ailes et al., 2015). As a child ages into adulthood, the chances of needing an additional procedure, surgery, or transplant increase.

Parental Stress

Raising a child with complex medical needs, such as CHD, can often lead to stress (Soulvie, et al, 2012). Abidin (1995) defined parenting stress as the stress that a parent experiences related to their child's characteristics and experiences in their parenting role. Abidin's definition of parental stress may account for how health-related uncertainty may lead to stress when raising a child with CHD. Parental stress can manifest in different ways depending upon the individual. While some parents may become depressed over their child's struggles, others may develop anxiety over their well-being (Solberg et al., 2011). While these are some potential internalizing symptoms of parental stress, parents may also externalize their stress via their parenting style with their children or marital satisfaction with their partner (Randall & Bodenmann, 2017).

Parental stress can arise from a multitude of different sources, and it can vary widely depending upon the lived experiences of caring for a child, as well as the child's

well-being. For the parents of a child with a disability, levels of perceived health can significantly impact parental stress (Nadeem, et al., 2016). Additionally, CHDs are a unique diagnosis that primarily impacts a child's physiology. However, as a child with CHD ages, secondary learning disabilities and psychiatric concerns arise at a higher prevalence than their counterparts (DeMaso et al., 2017). These differing sources of parental stress are elaborated in the following sections.

Parental Stress and Children with a Physical Disability

Past research has indicated that parents of children with physical disabilities perceive more parental stress than parents of children without CHD (Feizi et al., 2014; Pipp-Siegel et al., 2002). Pipp-Siegel et al. (2002) determined that mothers of young children with hearing loss perceived higher levels of stress as compared to other parents due to the increased hassles and lack of social supports attached to their child. Additional research by Uskun and Gundogar (2010) sought to ascertain what particular aspects of parenting a child with a physical disability lead to higher perceived stress than their typical parent counterparts. Findings indicated that the parents of physically disabled children were most stressed due to attitudes of society towards disabled people, having limited free time, and financial problems (Uskun & Gundogar, 2010). Furthermore, Darling, Senatore, and Strachan (2012) contended that daily parenting hassles, life events, and health changes impacted levels of stress more significantly among those with physically disabled children, such as deafness, as compared to non-disabled children.

Similarly, in a study done with parents/caregivers of children that were blind or deaf, there were significant differences in levels of perceived stress between these

caregivers and caregivers of other children (Feizi et al., 2014). The lifelong physical disabilities of deafness/blindness were shown to induce higher levels of parental stress than other chronic physical problems such as sensory-motor delays (Feizi et al., 2014). Malm-Buatsi et al., (2015) examined the relationship between parental stress and raising a child with spina bifida. They determined that parents raising a child with spina bifida perceived higher levels of stress than parents of other children. Additionally, the severity of the spina bifida was also shown to be proportional to the level of parental stress (Malm-Buatsi et al., 2015). Nadeem, et al. (2016) also explored parental stress among parents of children with and without physical disabilities. The physical disabilities denoted in this study were also deafness and blindness. Results indicated that parental stress was significantly higher among parents of children with these physical disabilities as compared to parents of healthy children (Nadeem, et al., 2016). It was noted that a perceived lack of supports being available for their child was one of the largest sources of stress.

Parental stress surrounding a child's physical disability can arise from areas beyond just perceived lack of societal support and financial concerns. Mörelius and Hemmingsson (2014) examined how a child's physical disability can lead to parental stress regarding their own health as well. They asserted that over 47% of children with moderate-to-severe motor disabilities, such as muscular dystrophy, possess severe sleep disturbances every night (Mörelius & Hemmingsson, 2014). These sleep disturbances necessitate constant assistance from their parents, which leads to exhaustion and poorer health status for these parents. The concerns surrounding their own health and lack of

sleep was shown to be a major contributor to psychological exhaustion and parental stress for these parents (Mörelius & Hemmingsson, 2014). Similarly, Lee at al. (2017) examined the health behaviors between family caregivers of children with and without physical disabilities. They concluded that the caregivers and parents of children with severe muscular disabilities and other physical disabilities reported significantly greater likelihoods of developing their own chronic conditions, such as migraines, back pains, high blood pressure, and obesity (Lee at al., 2017). Stress over their child's condition was frequently reported as a significant contributing factor for their stress and chronic conditions (Lee at al., 2017).

Parental Stress and Children with Chronic Illness

Raising and caring for children with a chronic illness can also have a significant impact on parental stress. In a 2013 study, caregivers of children with chronic illness reported significantly greater general parenting stress than caregivers of healthy children (Cousino & Hazen, 2013). Popp et al. (2014) contended that 41% of parents caring for a chronically ill child perceived high stress levels due to unresolved issues surrounding their child's diagnosis. These unresolved issues surrounded childhood diagnoses of asthma and type-1 diabetes, which were determined to possess varying long-term prognoses (Popp et al., 2014). These parents also reported lower levels of family functioning and spouse communication (Popp et al., 2014). Similarly, Miodrag et al. (2015) found that perceived levels of stress amongst parents of chronically ill children arose due to fear/uncertainty about their future health. Parents raising a child with a chronic illness reported significantly higher parental stress than the parents of healthy

children (Miodrag et al., 2015). Parental stress can also arise from differing sources depending upon the chronic illness being examined.

Cancer

Various cancer-related factors have been associated with parenting stress. One such factor was the recency of the child's diagnosis. Both Vrijmoet-Wiersma et al. (2010) and Sulkers, et al. (2015) reported that cancer-related parenting stress was greater for parents of children recently diagnosed with cancer. The highest levels of parenting stress were seen within the first three months of their child's diagnosis (Vrijmoet-Wiersma et al., 2010). In addition, there was a significant decrease in caregiving stress, depressive symptoms, and anxiety after these first three months (Sulkers, et al., 2015). Parents caring for a child with cancer that was newly diagnosed have also reported significantly higher levels of stress and anxiety during medical procedures (Harper, et al., 2013). These parents reported that keeping their children calm during these cancer-related procedures led to lower parenting self-efficacy and higher parenting stress (Harper, et al., 2013).

A child's activity limitations due to their cancer were also found to be associated with poorer parental quality of life and higher parenting stress (Litzelman, Catrine, Gangnon, & Witt, 2011). Parental perceptions of their child becoming weaker was shown to be a significant contributor to parental stress (Litzelman, Catrine, Gangnon, & Witt, 2011). Kazak et al., (2005) reported that 80% of parents of children with cancer demonstrated posttraumatic stress symptoms as their child's cancer progressed. In particular, the stress symptoms of avoidance and intrusive negative thoughts affected overall levels of parental stress and overall family functioning (Kazak et al., 2005).

Cystic Fibrosis

Cystic Fibrosis is a genetic disorder that affects the lungs, pancreas, liver, kidneys, and intestines (Gardner, 2007). It is a chronic disorder that severely affects the digestive and respiratory systems. Parents caring for a child with cystic fibrosis have reported higher parental stress than the parents of healthy children (Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Solomon & Breton, 1999). Parents of children with cystic fibrosis have reported that their children required more attentive parenting than healthy children (Solomon & Breton, 1999). When compared to other chronic childhood illnesses, Hullmann et al. (2010) found that parents of children with cystic fibrosis reported lower levels of parental stress than parents of children with asthma and diabetes. However, they also found that parents of children with cystic fibrosis reported higher perceived child vulnerability than parents of children with these other chronic illnesses (Hullmann et al., 2010). Ward et al. (2009) also asserted that child health vulnerability amongst children with cystic fibrosis can lead to problems with sleeping, eating and physiotherapy adherence. These symptoms were asserted to lead to poorer mental health, anxiety, and stress in these parents (Ward et al., 2009). Findings have generally asserted that the treatment necessary for cystic fibrosis is demanding and time consuming, both on parents and children (Cousino & Hazen, 2013).

Diabetes

Similar to other chronic illnesses, studies have suggested that parental stress when caring for a child with diabetes arises more from the child's behavior when adhering to illness management, rather than simply the illness, itself (Hilliard et al., 2011) and

(Streisand et al., 2015). Specifically, adhering the diabetic diets at restaurants was found to be a source of parental stress (Hilliard et al., 2011). Streisand et al. (2015) also contended that parents that take greater responsibility for their child's treatment regimen also perceive more stress. The severity of the child's diabetes was also shown to relate to parenting stress, as children with poorer metabolic control of their blood sugar was associated with parents with higher levels of perceived stress (Helgeson, Becker, Escobar, & Siminerio, 2012; Wu, Graves, Roberts, & Mitchell, 2010). Children with less care skills in managing their symptoms also led to parents having higher levels of stress (Helgeson, Becker, Escobar, & Siminerio, 2012).

Epilepsy

Epilepsy is a neurological disorder that is characterized by chronic seizures (Penfield & Jasper, 1954). Studies have shown that the presence of intractable seizures were associated with greater general parenting stress (Camfield, Breau, & Camfield, 2001; Shatla, et al., 2011). The severity of the seizure disorder was shown to be a larger contributor to parental stress than the frequency of the seizures (Camfield, Breau, & Camfield, 2001). Additionally, Rodenburg et al. (2007) found that, like other chronic illnesses, seizure-related child behavior problems significantly contributed to greater parenting stress. Prior to the onset of seizures, parents reported that their children would become noncompliant and defiant (Rodenburg et al., 2007). Similarly, Wirrell et al. (2008) found a significant correlation between behavior problems in the children and higher stress in their parents. These parents claimed that uncertainty and helplessness as to how to help their child was a significant source of stress (Wirrell et al., 2008).

Sickle Cell Anemia

Sickle cell anemia is a blood disorder that is an abnormality in the oxygen-carrying capabilities of red blood cells (Rees, Williams, & Gladwin, 2010). Logan, Radcliffe and Smith-Whitley (2002) found that greater disease-related parenting stress was associated with their children needing more frequent trips to health care services. Barakat et al. (2008) found that children with more frequent pain from their sickle cell anemia led to their parents perceiving greater disease-related parenting stress. These results were seen both in parents of young children (3–5 years) and adolescents (12–18 years) with sickle cell disease (Barakat et al., 2008). The parental perception about their child's levels of pain was shown to be a factor to parental stress levels as well (Smith et al., 2018). Smith et al. (2018) contended that parents who expressed satisfaction in their child's healthcare and their child's own sickle cell management also expressed lower levels of disease-related stress.

Asthma

For parents caring for a child with asthma, DeMore et al. (2005) found that greater medication adherence was associated with increased general parenting stress. However, Celano et al. (2011) asserted that better overall family management of asthma symptoms was also associated with less parenting stress. The existence of asthma paired with sleep-disordered breathing was associated with greater parenting stress (Fagnano et al., 2009). European American parents have reported that providing emotional support to their child with asthma was the most time-consuming caregiving task, while African

American parents have reported that managing tasks outside of the home was the most stress-inducing (Lee, et al., 2006).

Parental Stress and Children with Developmental Disabilities

Parenting stress can also arise due to cognitive and developmental concerns with their children. Gupta (2007) asserted that not only did the existence of a disability impact parental stress, but also the type of disability. Among four cohorts of children with diagnoses of ADHD, asthma, developmental disability, and HIV, the parents of the children with ADHD and a developmental disability reported the highest perceived parental stress (Gupta, 2007).-Additionally, multiple studies have emphasized that fewer child problem behaviors led to lower parenting stress scores (DeMaso et al., 2017; Uzark & Jones, 2003).

Valicenti et al. (2015) examined parental stress in families of children with autism and other developmental disabilities and its association with child comorbid symptoms. They found that parental stress was related mostly to child irritability, rather than the developmental disability diagnosis (Valicenti et al., 2015). They also contended that the child's sleep disturbances were a major contributor to parental stress over time (Valicenti et al., 2015). Woodman et al. (2015) conducted a 15-year longitudinal study that examined the varying levels of parental stress when raising a child with autism of differing ages. Results indicated that levels of parental stress at all ages were a significant predictor of child internalizing behavior (Woodman et al., 2015). Specifically, researchers identified that a child's increasing problem behavior was indicative of how stressed the parent appeared to be (Woodman et al., 2015).

Parental stress when raising a child with a developmental disability can also permeate other relationships within the family dynamic. Robinson and Neece (2015) explored the role that a developmentally disabled child's challenging behavior has on both parental stress and marital satisfaction. Their results indicated that lower marital satisfaction was most significantly associated with child problem behavior (Robinson & Neece, 2015). Additionally, they asserted that a strong martial satisfaction was not a contributing factor to alleviating the child's challenging behavior (Robinson & Neece, 2015). Findings also suggested that parental stress was impacted most significantly by child aggression, emotional reactivity, and sleep problems (Robinson & Neece, 2015). These findings suggest that the behavioral symptoms and byproducts of a diagnosis can impact stress more than the actual diagnosis.

Silva and Schalock (2012) examined the impact of stress between parents of children with autism and parents of neurotypical children. Results indicated that the parents of children with autism experienced higher levels of perceived stress (Silva & Schalock, 2012). More importantly, they asserted that the increased amount of stress felt by parents raising a child with autism arose from the social and communication-based deficits that the child possessed. This included comorbid behavioral issues and comorbid physical symptoms (Silva & Schalock, 2012). Similar to parents raising a child with a physical disability, these co-occurring challenges play a more prominent role in heightened parental stress than the primary diagnosis. As a result, the comorbid cognitive and psychosocial effects of a CHD diagnosis may become more impactful for parents compared to the initial challenges inherent in CHD (Silva & Schalock, 2012).

Diagnoses such as ADHD and anxiety have increasingly been seen within children with CHD (Demaso et al., 2017). Such neurocognitive deficits that can impact cognitive functioning occur as a side effect of surgical bypass, which restricts oxygen to the brain during corrective procedures (Sterken et al., 2016). Sterken et al.'s (2016) longitudinal study demonstrated that IQ scores of children with CHD were consistently eleven points lower than their counterparts during the first four years of life. Researchers noted that such potential deficits in cognitive development and psychosocial growth could lead to elevated levels of parental stress for these CHD parents (Sterken et al., 2016). Fears about delays in the cognitive development of CHD children is not a new phenomenon. A 2003 study found that that one in five parents of children with CHD had significantly elevated levels of stress arising from such fear about their child's lack of cognitive development (Uzark & Jones, 2003). The authors contended that higher levels of perceived stress were seen surrounding their child's cognitive development (Uzark & Jones, 2003). Since children with learning challenges such as ADHD and cognitive deficits such as lower early-life IQ experience more social and cognitive difficulties, their parents perceive higher levels of parental stress than do others with healthy children (Uzark & Jones, 2003). Gupta (2007) and Uzark and Jones (2003) have also asserted that attempting to manage child problem behavior and set limits/expectations were direct sources of parental stress.

With the higher psychiatric comorbidity and cognitive challenges of ADHD among children with CHD also comes the potential for other psychiatric diagnoses (Demaso et al., 2017). For example, anxiety disorders have been shown to be present to

individuals with CHD at a higher percentage than the general population (Demaso et al., 2017). When looking at children with single-ventricle CHD malformations, clinician-rated psychiatric evaluations have suggested that adolescents with CHD had higher rates of lifetime psychiatric diagnosis as compared to their peers. They specifically experienced higher rates of lifetime anxiety disorder and ADHD (Demaso et al., 2017). This higher risk of psychiatric morbidity would place additional stress upon parents as these children age. Researchers conducted a neurodevelopmental follow-up study with parents of both children with CHD and parents of children without CHD who reported their overall parenting stress levels based upon the perceived problem behaviors of their children (Sarajuuri et al., 2012). Results indicated that the parents of the children with CHD reported higher levels of stress based upon the emotional maladjustment of their children (Sarajuuri et al., 2012).

Parental Stress and Children with CHD

The psychological stress placed upon parents of children with CHD arises from the emotional stress of their child's cardiac illness (Hearps et al., 2014). CHD is a spectrum diagnosis, in that the severity of heart defect can range from mild to severe. In many mild cases, medical interventions may not be necessary. However, most severe cases of CHD necessitate complex surgery and palliative care. Whether prenatally or prior to surgical intervention during infancy, the shock parents experience when learning about their child's heart malformation has significant impacts on parental stress (Vrijmoet-Wiersma et al., 2009). Feelings of helplessness and vulnerability have been

shown to add to perceived stress, as CHD parents deal with a desire to understand the diagnosis and reconcile their healthcare choices (Doherty et al., 2009)

Solberg et al. (2011) conducted three longitudinal studies which evaluated the long-term symptoms of depression and anxiety among mothers of children with CHD. Between six and eighteen months postpartum, mothers of infants with severe CHDs showed significantly elevated levels of anxiety and depression (Solberg et al., 2011). The infant's medical prognosis and fear over their long-term quality of life were found to be the most impactful sources of anxiety and depression. Similarly, follow-up studies conducted a year later denoted the severity of the CHD as most impactful in the mother's emotional well-being, with the perceived availability of emotional supports serving as the only mitigating factor (Solberg et al., 2012).

Lopez et al. (2016) asserted that the uncertainty surrounding their child's survival was shown to be the overarching cause of hopelessness and parental stress prior to surgery. It was surmised that a child's successful surgery had a positive effect on parental hopelessness, but it did not impact parental stress or well-being (Lopez et al., 2016) It was also found that the parents of children with CHD possessed more stress after surgery than did the parents of healthy children (Lopez et al., 2016). In fact, similar research has ascertained that parental stress, both before and after surgery, lingered due to ongoing acceptance of their child (Uzark & Jones, 2003). Uzark and Jones (2003) and Hearps et al. (2014) suggested that a child with CHD may not match the expectations of the parents, which could lead to feelings of guilt and long-term stress. Parents of an infant

with CHD also perceived that their role as parents is less controllable and more stressful regarding their parental competency (Uzark & Jones, 2003).

Hearps et al. (2014) conducted a study assessing parental psychosocial risk factors four weeks after their children's corrective heart surgeries. This included measurement of infant risk factors of sleeping, feeding, crying, and bonding difficulties. From examining these infant-specific stressors, the researchers measured global psychosocial risk (including stress) amongst parents. Findings indicated that, while 61.5% of parents were classified as having the lowest risk after surgery, 38.5% of parents were classified as having heightened risk. Findings also concluded that 2.6% of these parents perceived clinically significant levels of psychosocial risk (Hearps et al., 2014). No differences in psychosocial risk were found based on type of congenital heart diagnosis (antenatal vs. postnatal). However, higher parent education significantly predicted lower psychosocial risk. Thus, while a majority of parents adapted to the acute stress of heart surgery on their child, a significant proportion of parents (38.5%) were found to have an increased psychosocial risk associated with higher rates of emotional distress (Hearps et al., 2014). The authors concluded that this heightened risk may impact the parental quality of life and capacity for optimal parenting (Hearps et al., 2014).

The likelihood of a child with CHD developing psychological or cognitive impairments such as ADHD or other behavior challenges is higher than in their typical peers (DeMaso et al., 2017). Children with CHD are already at high risk for neurodevelopmental deficits. These long-term childhood consequences may include attention and learning deficits, generalized anxiety, and depression (Rychik et al., 2013).

As a result of these challenges, many CHD parents maintain higher levels of stress relating to their child long after the emotional trauma of their corrective surgeries (Hearps et al., 2014). Moreover, Darling, Senatore, and Strachan (2012) found that parents of children with disabilities such as CHD experience greater overall stress in daily life. These sources of stress included parenting hassles, family life events and changes, parenting stress and health stress (Darling, Senatore, & Strachan, 2012).

Whether by becoming self-conscious due to their cardiac repair scars, or simply realizing their cardiovascular stamina does not match that of their typical peers, CHD children become more aware of their limitations with age (Lee & Kim, 2012). These realizations can lead to more psychosocial dysfunction for the children that, in turn, can lead to additional parental stress (Lawoko, 2007). These parents can typically experience loss of control, fear of bodily scarring, and resentment towards other children. These feelings may also place an emotional strain on the relationship between child and parent (Soulvie et al., 2012).

Lawoko (2007) found that parents of children with CHD experience psychosocial concerns and stress to a higher degree than other parents. As a result, they concluded that these CHD parents possess a higher need for psychosocial resources and support to improve parental satisfaction with the care of CHD (Lawoko, 2007). Similar to this study, a large amount of research highlights the need to establish additional supports to bolster parental coping when facing CHD (Bratt et al., 2015; Leon, Wallenberg, & Holliker, 2013; Rychik et al., 2013).

Parental Coping and Children with CHD

McCubbin et al. (1983) defines parental coping as a parent's response to managing demands when a child has a serious or chronic medical condition. For parents raising a child with CHD, the ability to cope with diagnosis and treatment can either exacerbate or aid in symptoms of parental stress (Leon et al., 2013). Rychik et al. (2013) found that higher levels of acceptance of CHD were associated with decreased amounts of depression and anxiety symptoms. Furthermore, they contended that higher levels of positive reinterpretation (seeing the positive side of things) were associated with decreased amounts of parental anxiety (Rychik et al., 2013). Conversely, higher levels of diagnosis denial were associated with increased instances of depression (Rychik et al., 2013). These findings indicate that a parent's ability to come to terms with a diagnosis and seek positive solutions significantly impacted their ability to alleviate parental stress.

Leon et al. (2013) concluded that parents raising a child with CHD must navigate a two-step cognitive appraisal pertaining to their child. The first step, appraisal of the stressor/problem, involves educating oneself about their child's CHD diagnosis. The second step involves an appraisal of what can be done to address the stressor/problem (Leon et al., 2013). This research indicated that a parent's ability to process, learn, and develop potential solutions for their child's medical challenge can serve to both mitigate stress and manage coping. The perception of support, despite which stage of cognitive appraisal, appeared to be the most prominent theme. This perceived support, in turn, has also been shown to enhance parental decision-making pertaining to the care of their child. Miller et al. (2011) examined the correlation between parental decision-making and

stress. Their findings indicated that a lack of education about their child's illness can directly lead to challenges in healthcare decision-making (Miller et al., 2011). It was also noted that a lack of decision-making added to perceptions of parental stress and future abilities to cope.

Acknowledging the importance of social support and education appears significant to properly coping and minimizing parental stress. For example, Bratt et al. (2015) stated that the parents' ability to cope effectively with their child's diagnosis was significantly heightened by medical staff increasing their knowledge and understanding of CHD. Having medical staff educate parents about CHD aided significantly in parents feeling supported (Bratt et al., 2015). It was also found that decreasing the waiting time for a specialist evaluation, coupled with clear and straightforward CHD information was essential in bolstering positive coping skills (Bratt et al., 2015). For parents to effectively process a CHD diagnosis, the proper education and explanation must be in place. Furthermore, one's ability to come to terms with their situation plays an important role in their ability to cope with stress (Whiting, 2014). Both the initial emotional impact, as well as the subsequent perceived need for help and support directly impacted participants' ability to cope.

Whiting (2014) asserted that when parents discover a complex health concern in their children, their ability to cope depends on how they search for external sources of care and how they perceive that care and support is provided. It was concluded that it is important for healthcare professionals to be aware of their own interpersonal communication and engagement with families (Whiting, 2014). Allowing the parents to

feel supported and properly educated greatly aids one's ability to cope with a challenging diagnosis. Bruce, Lilja, and Sundin (2014) agreed with these findings and concluded that mothers receiving this kind of person-centered and family centered care feel more supported. These perceptions of support directly lead to an increased ability to adapt to the stresses of parenting a child with CHD (Bruce, Lilja, & Sundin, 2014). Equally important to being educated on the medical intricacies of a CHD diagnosis is the presence of emotional support in the forms of sympathy, confidence, being treated with respect, and being taken seriously (Bruce, Lilja, & Sundin, 2014). Studies have also concluded that the ongoing existence of emotional support has bolstered parental confidence/ability to cope (Ahn et al., 2014; Burke et al., 2014).

Burke et al. (2014) explained that long-term programs and support groups can serve a significantly positive role in bolstering levels of parental coping. For parents of children with life-threatening illnesses, a pilot program was conducted that employed acceptance and commitment therapy with problem-solving skills training (Burke et al., 2014). After six months of therapy, findings indicated that parental problem-solving skills and emotional well-being were greatly improved from baseline levels (Burke et al., 2014). This seems to demonstrate that having long-term supports available to parents of sick children can dramatically aid both their ability to cope and psychological well-being. Such support systems also enhance communication skills between couples and amongst parents in similar situations. Ahn et al. (2014) also conducted a study wherein the parents of adolescents with CHD were assessed for their coping strategies, as well as their ability to communicate with their child about their condition. Results were consistent with

previous research, as they indicated that medical professionals should develop structured intervention programs for both CHD patients and their parents in order to enhance coping, communication, and knowledge (Ahn et al., 2014). Acknowledging the presence of others in similar situations has also been shown to alleviate sources of parental stress and worry (Doherty et al., 2009).

Rempel et al. (2013) explained that there are overlapping and reemerging phases of parental coping when raising a CHD child. These phases include: 1) realizing and adjusting to the inconceivable; 2) growing increasingly attached; 3) watching for and accommodating the unexpected; and 4) encountering new challenges (Rempel et al., 2013). Rather than simply overcoming a difficult period, it was acknowledged that medical concerns, setbacks, and complications can arise at any point during a child's development. As a result, it was suggested that social, psychological, and medical supports should aim to safeguard parents utilizing a more long-term approach (Rempel et al., 2013).

Another prominent factor that can considerably impact both parental stress and coping is psychosocial support from one's partner (Werner et al., 2014). A parent's ability to navigate the coping phases and cognitive appraisals of their CHD child can either be aided dramatically or diminished by their perceptions on marriage satisfaction. The following section will address the literature pertaining to the relationship between raising a child with CHD and marriage satisfaction.

Marriage Satisfaction and Children with CHD

Marriage satisfaction refers to the degree to which partners assess their approval of different aspects of their marital relations (Arrindell, Boelens, & Lambert, 1983). In most romantic relationships, stress can have a substantial impact on marital satisfaction. Randall and Bodenmann (2017) elaborated upon Bodenmann's stress-divorce model by addressing how everyday stressors can influence relationship functioning. They asserted that stressors originating outside the relationship (external stressors) can spillover into a relationship and cause stress within the relationship (internal stress) (Randall & Bodenmann, 2017). Typically, these external stressors can be financial constraints, social life, or medical concerns. For couples raising a child with any kind of disability, marriage/relationship satisfaction can be negatively affected compared to the normal population (Hatton et al., 2010). More specifically, a child's disability may add to perceived levels of parental stress (stress, anxiety, and depression) and contribute to fragments within the familial dynamic (Hatton et al., 2010). Weitlauf et al. (2014) contended that previous relationship quality and high parenting stress were related to higher incidence of depression amongst mothers of children with autism. Further, they asserted that a strong positive relationship with their partner mitigated the likelihood of developing depression (Weitlauf et al., 2014). When applied to parents of children with CHD, parental stress, anxiety, and depression were common after prenatal diagnoses are discovered (Rychik et al., 2013). It has been theorized that positive partner relationships and stronger social support networks can mitigate these emergent emotional concerns (Rychik et al., 2013; Werner et al., 2014).

Rychik et al. (2013) commented that there is normally an increase in partner satisfaction that naturally occurs within a couple when they become pregnant. However, their sample population of parents of children with CHD reported lower overall partner satisfaction as compared to normal pregnant samples (Rychik et al., 2013). These same partners also reported significantly higher levels of anxiety and stress symptoms (Rychik et al., 2013). This study suggested that a diagnosis of CHD can potentially create conflict within couples. Rychik et al. (2013) concluded that relationship-based conflicts arise for multiple reasons. Among these are differences in opinion concerning continuation of pregnancy and negotiating decisions that are necessary in continuing care before and after birth (Rychik et al., 2013). Furthermore, the perception of a change in future life with the added burden of caring for a child has also shown to contribute to partner dissatisfaction (Werner et al., 2014).

Berant et al. (2003) contended that marriage satisfaction is determined by availability of emotional support and stability, rather than the child's CHD diagnosis alone. It has been suggested that poor communication, role incongruity, and lack of intimacy can cause marital dissatisfaction within the CHD parent population (Berant et al., 2003). Berant et al. (2003) determined that while the severity of a child's CHD played a role in marriage satisfaction, a mother's ability to become attached to their child also affected satisfaction with their partner. In other words, how these mothers appraised their new relationship with their CHD child also influenced their perception/satisfaction with their partner. The mothers also reported that maintaining a positive view on marital satisfaction emboldened their ability to cope with their child.

Similarly, Dale et al. (2013) explored relationship satisfaction amongst mothers of children with CHD and their partners. They compared the relationship satisfaction rates of CHD mothers to those of mothers of children without CHD. They found that having a child with a CHD, regardless of severity, did not directly impact the decline of relationship satisfaction from 18-36 months postpartum (Dale et al., 2013). The researchers hypothesized that families of chronically ill children might seek to restore emotional balance and promote well-being in response to stress (Dale et al., 2013). As a result, CHD parents might compensate and work harder to overcome these heightened stressors in their lives. Additionally, the mothers of children with CHD did not report a higher percentage of divorce or separation at 36 months postpartum compared with the control group (Dale et al., 2013). This showed that relationship satisfaction 18-36 months postpartum return to levels similar to the general population.

These findings were reinforced by Brenner et al. (2016), who explored family functioning and parental separation/divorce rates among couples caring for a child with severe CHD. They found that CHD parents did not appear to be at higher risk for separation/divorce within the first 17 months after birth (Brenner et al., 2016). In fact, Leon, Wallenberg, and Holliker (2013) indicated that a preexisting strong marital satisfaction can serve as a positive source of coping when facing a child with a CHD diagnosis. They found that there was a significant correlation between partner satisfaction, positive coping, and the use of emotional social support (Leon, Wallenberg, & Holliker, 2013). It was suggested that although individual coping skills are important, partner satisfaction may be a better predictor of parental resilience when facing a prenatal

CHD diagnosis (Leon, Wallenberg, & Holliker, 2013). As a result, much of the literature pertaining to CHD parents and marriage satisfaction expressed the need for social support systems, such as marital counseling, to be available to cultivate and maintain positive levels of satisfaction.

Summary and Conclusions

Previous research has indicated that parents of children with CHD possess higher perceived levels of stress as compared to the parents of children without CHD (Rassart, 2013). Additionally, studies looking at the sources of stress for parents of children with CHD have found that uncertain future health, additional financial burdens, and comorbid child behavior challenges heighten this parental stress (Nadeem, et al., 2016; Soulvie et al., 2012). Furthermore, it has been asserted that higher levels of stress within any couples' relationship can negatively impact overall marriage satisfaction (Randall & Bodenmann, 2017). Minuchin's structural family theory seems to support these findings, as it asserts that stress and maladaptive behavior can develop within a family when it cannot adapt to severe internal or external burdens (Minuchin, 1974). This relationship between burden and stress has also been shown to impact levels of family functioning and marital satisfaction (Mitrani et al., 2006).

While previous research has uncovered a relationship between parental stress and CHD, it has not addressed the impact parental stress has on the marriage satisfaction of parents with children with CHD. In addition, studies have not examined the relationship between stress, coping, and their impact on marriage satisfaction amongst parents with children with CHD. This research is important as CHD can place parents at a higher risk

of psychosocial dysfunction than their counterparts with children without CHD (Hearps et al., 2014). Therefore, the present study sought to address the impact that parental stress, parental support, and coping had on the marriage satisfaction of parents with children with CHD. Such research could be utilized to help identify specific methods of psychological support, such as CHD-focused couple's therapy and CHD parent support groups. Chapter 3 will include a review of the research design/rationale. Also, a review of the methodology will include a description of population, sampling procedures, procedures for recruitment/participation, data collection, instrumentation and operationalization of constructs, threats to validity, and ethical procedures.

Chapter 3: Research Methods

Introduction

The purpose of this study was to examine the relationship between parental stress, parental support, and parental coping on marriage satisfaction among parents with children with CHDs. In this chapter I describe how the research design, the population, and sampling procedures were used. Also, I address how the data were measured, collected, and statistically analyzed.

Research Design and Rationale

The variables in this study were parental stress, parental support, parental coping, and marriage satisfaction. Specifically, I examined the extent to which parental stress, parental support, and parental coping related to marriage satisfaction among parents of children with CHDs. The independent variables included four parental stress scores, one parental support score, and three parental coping scores. Parental stress included four scores from the Parenting Stress Index Short Form (parental distress subscale, parent-child dysfunctional interaction subscale, difficult child subscale, and the total stress score; Abidin, 1990b). Parental support included one score from the Parenting Stress Index Long Form (the spouse/parenting partner relationship subscale; Abidin, 1990a). Parental coping included the three subscales of the Coping Health Inventory for Parents (maintaining family integration, cooperation, and an optimistic definition of the situation; maintaining social support, self-esteem, and psychological stability; and understanding the medical situation through communication with other parents and consultation with medical staff; McCubbin et al., 1983). The dependent variable was marriage satisfaction,

as measured by the two subscales of the ENRICH Marital Satisfaction Scale (idealistic distortion and marital satisfaction), as well as a total marriage satisfaction score (Fowers and Olson, 1993).

The nature of the study was a quantitative, non-experimental correlational design. The need to explore the relationship between these variables and gather data in a natural setting was most appropriate to the use of a correlational design (Frankfort-Nachmias & Nachmias, 2008). Since my goal was to find correlations and relationships between chosen variables, this design was also suitable for my research questions. For survey research, a correlational design is the most commonly used. A correlational design can also gather information on relationships between multiple variables while remaining mostly observational in nature (Stangor, 2011). Correlational designs often use surveys and a larger number of participants. Because this study collected information from one specific population, it was an appropriate design (Frankfort-Nachmias & Nachmias, 2008).

Methodology

Population

The target population consisted of parents of children with congenital heart defects from the United States who are married. Couples were not recruited for this study. Rather, only one member of a couple could participate. I anticipated that a majority of the participants would be female, as they typically tend to assume the role of primary caregiver. I recruited participants from online, via a variety of national and local support/advocacy groups. I was able to recruit participants from a variety of ethnicities

and backgrounds. The parents must have had a child with a CHD that had been diagnosed by a medical professional. The participants must also have been living with their child/children.

Sampling and Sampling Procedures

Participants for this study were acquired from a nonprobability convenience sample. I used a nonprobability convenience sample because it involved the selection of the most accessible subjects and because it is not costly in terms of time, effort, and money (Marshall, 1996). Parents were recruited from online national and local CHD support groups, as well as online local and national parent/advocacy groups. Some national CHD support groups that were contacted included: Kids with Heart NACHD, Little Hearts, and the Children's Heart Foundation. The Children's Heart Foundation, for example, is a national advocacy group for parents of children with CHD. I am a member of their New York chapter. The parents needed to be at least 18 years of an age. There was also a screening question asking if English was their first language. If English was not their first language, participants were excluded from this study. They also must have been married and the biological parents of a child with a CHD. Also, they must have been able to read at a high school reading level, since the involved survey was written at that educational level. There were no criteria necessary for having/not having other children. There was no minimum number of years required for these parents to be married. Exclusion criteria included parents who were divorced or not currently living together. Also, parents who had not had their child in their custody or guardianship for at least 2 years were excluded.

I conducted a power analysis for multiple regression using the software G*Power to determine sample size (Faul, Erdfelder, Buchner, & Lang, 2009). I selected an α (error probability or significance level) of .01, a power level of .95, an effect size (f^2) of .15 (a medium effect size), with eight predictor variables. A more conservative .01 level was used due to the number of variables included in this study and likelihood of type 1 error. Based upon a review of the literature, a medium effect size had most often been utilized in studies analyzing these topics. For example, Dale et al. (2013) incorporated a medium effect size when looking at the association between relationship satisfaction and raising a disabled child. Moreover, Miodrag et al. (2015) also found a medium effect size when examining the relationship between parental stress and a child's chronic health concerns**.** The resulting suggested sample size was 206 participants.

Procedures for Recruitment, Participation, and Data Collection

Upon IRB approval, I began recruiting participants. For this study, there was one type of recruitment procedure. Information introducing the study was disseminated online via national parent support websites/groups, advocacy groups, and social media outlets. Since I am a member of several local parent organizations, such as the Children's Heart Foundation and Gavin's Got Heart, I was able to gain access to these groups. To garner additional participation, I made connections at other online support groups and other local CHD organizations that I am currently unaffiliated with. I identified several of these additional organizations. They included Wear Red or Go Naked, which is a local CHD parent and advocacy group, and Mended Little Hearts, which is a charitable foundation

serving the CHD community. Once I had communicated with these local organizations online, I asked permission to distribute recruitment materials via social media.

Individuals interested in participation in the study were directed to a link where they were able to give informed consent and complete all survey questions. When clicking into the link, the first page of the online software requested informed consent for participation in the survey. As part of informed consent, all participants were informed of their rights. It also included background information on the study, procedures for participation, confidentiality information, the voluntary nature of the study, and any ethical concerns. The form also notified the participant that their child's CHD must be current and diagnosed by a medical health professional. The form informed participants that they are free to withdraw their consent and end their participation at any time. The informed consent form also apprised participants of what the data will be used for. Participants were also shown a sample survey question from each scale. They were also given my contact information, should any concerns/questions arise. Finally, consent covered both the benefits for participating and a guarantee of confidentiality (Creswell, 2014).

The second page was a brief demographic form (see Appendix A). This form inquired as to the age, gender, educational background, ethnicity, annual income, and marriage length of participants. Parents were also asked to report information pertaining to their child with CHD. These items included: child's current age, which CHD was diagnosed, age at time of diagnosis, and number of total children in the household. Examples of possible diagnoses were provided from a drop-down menu. Since this is a

one-time data collection study, it did not have any follow-up procedures. Participants exited the study by being thanked for their participation. They were also given a summary of the results if they requested it.

Instrumentation and Operationalization of Constructs

The Parenting Stress Index-4 Short Form (PSI-4 Short Form)

The Parenting Stress Index was developed by Richard Abidin in 1990 to measure the stress in parenting. The Parenting Stress Index-Short Form (PSI-4 Short Form) features 36 items drawn from the Long-Form's 120 items. The PSI-4 Short Form was used to measure parental stress for this study. The PSI-4 Short Form is divided into three domains (parental distress, parent-child dysfunctional interaction, and difficult child; Abidin, 1990b). These subscales combine to form a total parental stress score. The parental distress subscale measures the amount of stress experienced within the parenting role. It measures spousal conflicts, competence, depression, restrictions felt by the parent, and social support. An example item is "I often feel I cannot handle things well" (Abidin, 2012). The parent-child dysfunction subscale measures how a parent may feel that a child meets his/her expectations and how satisfied he/she is with their interactions with the child (Abidin, 2012). An example item is "My child rarely does things for me that make me feel good (Abidin, 2012). The difficult child subscale measures how challenging the parent perceives their child to be (Abidin, 2012). An example item is "My child seems to cry or fuss more often than most children" (Abidin, 2012). The total stress score indicates the overall level of parenting stress. There is a validity scale

included in the short form made up of 7 items that measure defensive responding, or whether a participant is responding in a defensive manner.

The PSI-4 Short Form has demonstrated high reliability as a measure of parental stress. Internal consistency of the PSI-4 (both long and short form) was found to be good, with subscales ranging from $\alpha = 0.75$ for parental distress, $\alpha = 0.83$ for parent-child dysfunctional interaction, and $\alpha = 0.87$ for difficult child (Barroso, Hungerford, Garcia, Graziano, & Bagner, 2016). The Cronbach's alpha for the total stress score was $\alpha = 0.96$, which indicated high internal consistency (Barroso et al., 2016). For the PSI-4 Long Form, reliability coefficients between the subscales for the parent domain (where the spouse/parenting partner relationship subscale resides) were all found to be between r = 0.75 and 0.87 (Abidin, 2012). In general, internal consistency for the PSI-4 Long Form as measured by Cronbach's alpha was found to be good. All subscales have $\alpha = 0.88$ to 0.90. Test-retest reliability after one year for the total stress scale was $r = 0.84$ and ranged from $r = 0.68$ to $r = 0.85$ for the subscales (Lee, Gopalan, & Harrington, 2016).

The PSI-4 Short Form has also been shown to possess good validity in previous research. Several studies have found that when parents demonstrated higher levels of parental stress, as measured by the PSI-4 Short Form's total stress score, they were more likely to manifest depressive symptoms (Anthony et al., 2005; Neece et al., 2012; Ross, 2013). Parents with a developmentally disabled child also had higher total stress scores when their children tended to exhibit more behavior problems (Neece et al., 2012; Valicenti et al., 2015). Valicenti et al. (2015) utilized the PSI-Short Form with 49 families of children with autism spectrum disorder. After a multivariate logistic

regression analysis, high scores on the PSI- Short Form were significantly associated with those experiencing challenging behaviors in their children (Valicenti et al., 2015). Similar results were found in Robinson and Neece's (2015) study. They also reported that higher levels of parenting stress were significantly associated with higher levels of child behavior problems, including total, externalizing, and internalizing behavior problems (Robinson & Neece, 2015). The PSI-Short Form's total stress scale demonstrated the best sensitivity and specificity for predicting maternal depressive symptoms with clinically significant T-scores above 75% (Barroso et al., 2016).

Scores on the PSI-4 Short Form range from 36-180. Higher scores indicate higher levels of parenting stress, with total stress scores in the 91st percentile or higher being considered clinically significant (Abidin, 1990b). The average time for completion of the short form is 10 minutes. I acquired the instrument for online use from the publisher. A licensing agreement was required for use of this assessment. The PSI-4 (both long and short forms) uses a 5-point Likert scale from *strongly agree* to *strongly disagree*. Both scales were normed on over 1,000 parents to identify the dysfunctions of parenting and potential adjustment problems in children (Abidin, 1990a). Both scales can be completed with a fifth-grade reading level. A permission agreement was reached with Pearson for the use of these assessments.

The Parenting Stress Index-4 Long Form: Spouse/Parenting Partner Relationship Subscale (PSI-4)

The subscale of Spouse/Parenting Partner Relationship within the Parental Domain of the Long Form PSI-4 was used to measure parental support in this study**.** The

spouse/parenting partner relationship subscale assesses the parent's perception of emotional and physical support from the parenting partner (Abidin, 1990a). Higher scores on this subscale signify a lack of emotional and active support of the other parent in the relationship. This subscale consists of 7 items. An example question is: “Having a child has caused more problems than I expected in my relationship with my spouse/parenting partner” (Abidin, 1990a). This subscale was originally designed to examine the stresses experienced in a traditional dyad family structure. However, it has been revised to incorporate wording that addresses a broader and more diverse range of family structures (Abidin, 2012).

Research has also documented positive correlations between the parental distress subscale and parenting behaviors, including negative parenting practices and emotional responsiveness (Haskett et al., 2006). Construct validity has been noted in numerous studies. The PSI showed that higher levels of parental stress significantly impacted parenting self-efficacy and positively related to the number of family risk factors (Raikes & Thompson, 2005). Multivariate analysis showed that parenting self-efficacy accounted for 33% of the variance in parenting stress scores (Raikes & Thompson, 2005). Another study showed that high scores in the PSI-Short Form difficult child subscale correlated significantly in the mothers of infants that were most easily frustrated (Calkins, Hungerford, & Dedmon, 2004). This indicated that higher scores on the difficult child subscale predicted greater parenting stress amongst mothers with more easily frustrated infants (Calkins, Hungerford, & Dedmon, 2004). In another study by Haskett et al. (2006), abusive parents scored significantly higher on the total score of the PSI than non-

abusive parents (Haskett, Scott, Willoughby, & Nears, 2006). Further, Barroso, et al. (2016) examined mothers of young infants with elevated problem behaviors.

Similarly, the PSI-4 has been used in multiple studies measuring parenting stress, including those measuring stress in parents of children with various disabilities. Anastopoulos et al. (1992) utilized the PSI-4 long form to examine the relationship between parenting stress and raising a child with ADHD. They found a significant correlation between parenting stress and ratings on the depression and parent health subscales of the PSI-4 (Anastopoulos et al., 1992). Similarly, Hutcheson and Black (1996) reported the most significant correlations of parenting stress arising from the parent health and depression subscales. They reported that the PSI-4's validity as high. Through self-reports and observational measures, PSI-4 scores were consistent with previously reported stress measures across samples that vary in ethnicity and socioeconomic status (Hutcheson & Black, 1996). Additionally, Chiou and Hsieh (2008) utilized the PSI-4 long form to measure parenting stress of couples raising children with asthma and epilepsy. They reported that the PSI-4 validated previous research into parenting stress, with particular regard to a child's problem behavior (Chiou & Hsieh, 2008).

The Coping Health Inventory for Parents

The Coping Health Inventory for Parents was developed by McCubbin (1983) to measure parental coping with a child with a serious or chronic illness. The Coping Health Inventory for Parents is a 45-item measure of a parent's response to managing demands when a child has a serious or chronic medical condition (McCubbin et al., 1983). It has

three subscales: (a) maintaining family integration, cooperation, and an optimistic definition of the situation; (b) maintaining social support, self-esteem, and psychological stability; and (c) understanding the medical situation through communication with other parents and consultation with medical staff (McCubbin et al., 1983). There is no total coping score for this scale. The first subscale involves advocating for family connectedness when facing child illness. The second subscale represents a partner's ability to act as an emotional and psychological buffer for his/her partner. The third subscale signifies an understanding of a child's illness and aiding in subsequent supports/knowledge (Gothwal, Bharani, & Reddy, 2015).

The Coping Health Inventory for Parents uses a 4-point Likert-type scale from not helpful to extremely helpful. An example item is: "Trying to maintain family stability and talking with the doctor about my concerns about my child with the medical condition" (McCubbin et al., 1983). The scale was normed on 308 parents of chronically-ill children. Each of the three subscales has been shown to possess adequate internal reliability. Cronbach alphas for the 3 subscales have been reported as .79, .79, and .71 (Gothwal, Bharani, & Reddy, 2015).

The Coping Health Inventory for Parents is a widely used measure in studies of children with chronic illnesses and disabilities (Goldbeck, 2001; Mastroyannopoulou et al., 1997). Its validity has been analyzed in several studies. Zanon et al., (2017) measured parental coping within a population of Brazilian parents. They concluded that the rating scale analyses of the Coping Health Inventory for Parents possess good psychometric properties and works well to measure the coping patterns of parents raising children with

disabilities (Zanon et al., 2017). Goldbeck (2001) also utilized the Coping Health Inventory for Parents to measure parental coping in relation to parenting stress and childhood illnesses. They found that the scale showed a significant correlation between the parents' possessing a positive religious coping style and a higher self-reported quality of life ($r=0.60$, $p<0.001$) (Goldbeck, 2001). These findings also mirrored the results from Larson et al. (1994), who found a positive correlation between couples who actively seek social and religious support with an improvement of parental quality of life. Additionally, Mastroyannopoulou et al. (1997) studied the parents of children with life-threatening illnesses. They implemented the Coping Health Inventory for Parents and determined that couples characterized by higher conflict and less social support were more susceptible to psychological stress (Mastroyannopoulou et al., 1997). Lakkis, et al. (2016) examined the relationship between the existence of coping strategies and psychological stress in parents of children with cancer. They also found a significant positive relationship, using the Coping Health Inventory for Parents, between social support and maintaining family integration (Lakkis, et al., 2016). These same items appeared statistically relevant in Goldbeck's (2001) study and Larson et al.'s (1994) study.

This survey was within the public domain and had been acquired for use within this study. For best practice, I was able to communicate with the author and obtain his agreement to use this tool. The average time for completion of the Coping Health Inventory for Parents is 30 minutes.

The ENRICH Marital Satisfaction Scale

The ENRICH Marital Satisfaction Scale (EMS scale) is a method for measuring marriage satisfaction developed by Fournier, Olson, and Druckman (1983). It is a 2-subscale inventory and includes a total of 15 items. These two subscales are the Idealistic Distortion subscale (5 items) and the Marital Satisfaction subscale (10 items). The ENRICH Marital Satisfaction Scale uses a 5-point Likert-type scale from strongly agree to strongly disagree. The Idealistic Distortion subscale assesses the tendency for individuals to respond to statements in a socially desirable manner (Fowers & Olson,1989). It measures the extent to which a person distorts their relationship in a positive direction. These individuals may also resist acknowledging and discussing the problematic areas of their relationships (Fowers and Olson, 1989). An example item from the Idealistic Distortion subscale is: "Our relationship is a perfect success" (Fournier, et al., 1983). Idealistic distortion is scored in a negative direction and is used to revise the scores of the marital satisfaction subscale in a downward direction (Fowers et al., 1992b). An example item from the Marital Satisfaction subscale is: "I am very happy about how we make decisions and resolve conflicts" (Fournier et al., 1983). Each of the 10 Marital Satisfaction items represents one of the areas of the marital relationship assessed by the full-length ENRICH Inventory (e.g. communication or sexual relationship) (Fowers & Olson, 1993).

The 5 items from the Idealistic Distortion scale establish a marital conventionalization scale. It correlates highly with other scales that measure marital conventionalization and has an alpha coefficient of .92 and a 4-week test-retest reliability

of .92 (Olson et al., 1987). The EMS Scale was evaluated for internal consistency and test-retest reliability. Cronbach's alpha revealed an internal reliability of .86. Test-retest reliability was assessed with 115 individuals over a period of 4 weeks. The reliability coefficient over this time was .86. Item-total correlations were conducted to further assess the degree to which the items form a cohesive scale. The item-total correlations for the Marital Satisfaction scale items were found to be strong, ranging from .52 to .82 with a mean of .65 for men and .68 for women.

Within a national study of 1,200 couples, the EMS Scale had a correlation of .73 with the Locke-Wallace Marital Adjustment Test (Locke & Wallace, 1959) using individual scores and .81 with couple scores (Olson et al., 1989). This demonstrated that the EMS Scale is consistent with other accepted valid measures of marriage satisfaction. The EMS Scale was compared with a single-item measure of satisfaction with 7,261 couples by Fowers and Olson (1989). The EMS Scale had correlations of .71 for men and .77 for women with the single-item satisfaction measure. This is consistent with the strength of relationship between other satisfaction scales and single-item measures (e.g., Huston, McHale, & Crouter, 1986). An earlier study found that the EMS Scale had correlations of .71 (couple scores) and .66 (individual scores) with the Family Satisfaction Scale (Olson et al., 1989).

Olson et al. (1989) also examined cross-sectional variations in marital satisfaction across the family life cycle. It was found that marital satisfaction is highest before a couple has children and after the children leave home. This pattern was found for both the EMS Scale and MAT. Divorce tendency has been established as a related but separate

indicator of marital quality (Booth, Johnson, & Edwards, 1983; Order & Bradbury, 1968; Weiss & Cerreto, 1980). It was stated that a moderate relationship between thoughts of divorce and the EMS Scale would also provide confirmation of the EMS Scale's construct validity. The single-item divorce question correlated with the EMS Scale (r =.48 for men and r =.56 for women). These correlations are consistent with the relationships other marriage satisfaction measures have shown with these factors (Fowers & Olson, 1993).

In recent years, the ENRICH Marital Satisfaction Scale has been utilized in several studies to assess marital satisfaction. Pandya (2019) used the EMS scale to measure marriage satisfaction amongst highly qualified professionally achieving women pre and post-retirement. They reported the Cronbach's alpha coefficient of the EMS Scale for their study to be 0.93 (Pandya, 2019). Weinberg et al. (2018) utilized the EMS scale to examine marital satisfaction and trauma-related symptoms among injured survivors of terror attacks. The Cronbach's alpha coefficient of 0.96 was reported for both the survivors and spouses (Weinberg et al., 2018). Also, Maroufizadeh et al. (2019) measured marital satisfaction using the ENRICH Marital Satisfaction Scale amongst couples struggling with infertility. They reported a Cronbach's alpha coefficient of the EMS Scale of 0.77. Permission was given to use this survey from Dr. Blaine Fowers, one of its creators, for use in this study. The average time for completion of the EMS scale is 10-15 minutes.

Data Analysis Plan

The quantitative data collected in this study provided a measurement of marriage satisfaction as impacted by parental stress, parental support, and parental coping. The independent variables were the four components of parental stress (parental distress subscale, parent-child dysfunctional interaction subscale, difficult child subscale, and total stress score), one component of parental support (spouse/parenting partner relationship subscale), and the three components of parental coping (maintaining family integration, cooperation, and an optimistic definition of the situation; maintaining social support, self-esteem, and psychological stability; and understanding the medical situation through communication with other parents and consultation with medical staff). The dependent variables were the three components of marriage satisfaction (idealistic distortion subscale, marital satisfaction subscale, and the total marriage satisfaction). The demographic variables collected by the demographic questionnaire were used as a participant screening process. Internal consistency of the data was analyzed by Cronbach's alpha to test these scales relative to my population. SPSS was used to enter and analyze the data. SPSS was also utilized to determine the means, standard deviations, and variance of responses to these surveys.

Tests to validate the assumptions of multiple regression were completed prior to the main analyses. The dependent variable of marriage satisfaction is an interval variable measured on the continuous scale, which satisfies the assumption of multiple regression analysis (Frankfort-Nachmias & Nachmias, 2008). The independent variables of parental stress, parental support, and parental coping are also interval variables measured on the

continuous scale. The following assumptions were also evaluated: linear relationship between the variables, normality, multicollinearity, no auto-correlation, and homoscedasticity (Frankfort-Nachmias & Nachmias, 2008). Linearity was tested using a SPSS scatterplot. Normality was determined by using a Q-Q plots. To ensure that the independent variables are independent from one another, a multicollinearity diagnostic was performed in SPSS. To ensure no auto-correlation, a Durbin-Watson's *d* test was conducted. Finally, a standardized residual plot was done to determine homoscedasticity. These tests for assumptions were completed before the multiple regression analyses. Data was analyzed using multiple regression via SurveyMonkey. A detailed report of these tests and assumptions will be given in Chapter 4.

The following were the research questions and hypotheses for this study:

Research Question 1: To what extent does the parental distress component of parental stress, as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$1: Parental distress is not a significant predictor of marriage satisfaction.

H_a1: Parental distress is a significant predictor of marriage satisfaction.

Research Question 2: To what extent does the parent-child dysfunctional interaction component of parental stress, as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$2: Parent-child dysfunctional interaction is not a significant predictor of marriage satisfaction.

H_a2: Parent-child dysfunctional interaction is a significant predictor of marriage satisfaction.

Research Question 3: To what extent does the difficult child component of parental stress (i.e., how challenging the parent perceives the child to be), as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$3: Difficult child is not a significant predictor of marriage satisfaction.

H_a3: Difficult child is a significant predictor of marriage satisfaction.

Research Question 4: To what extent does the parental stress total score, as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$4 Parental stress is not a significant predictor of marriage satisfaction.

H_a4: Parental stress is a significant predictor of marriage satisfaction.

Research Question 5: To what extent does the spouse/parenting partner relationship component of parental support, as measured by the Parenting Stress Index-4 Long Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$5: Spouse/parenting partner relationship is not a significant predictor of marriage satisfaction.

H_a5: Spouse/parenting partner relationship is a significant predictor of marriage satisfaction.

Research Question 6: To what extent does the maintaining family integration, cooperation, and an optimistic definition of the situation component of parental coping, as measured by the Coping Health Inventory for Parents, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$6: Maintaining family integration, cooperation, and an optimistic definition is not a significant predictor of marriage satisfaction.

H_a6: Maintaining family integration, cooperation, and an optimistic definition is a significant predictor of marriage satisfaction.

Research Question 7: To what extent does the maintaining social support, self-esteem, and psychological stability component of parental coping, as measured by the Coping Health Inventory for Parents, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$7: Maintaining social support, self-esteem, and psychological stability is not a significant predictor of marriage satisfaction.

H_a7: Maintaining social support, self-esteem, and psychological stability is a significant predictor of marriage satisfaction.

Research Question 8: To what extent does the understanding the medical situation through communication with other parents and consultation with medical staff component of parental coping, as measured by the Coping Health Inventory for Parents, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$8: Understanding the medical situation through communication with other parents and consultation with medical staff is not a significant predictor of marriage satisfaction.

H_a8: Understanding the medical situation through communication with other parents and consultation with medical staff is a significant predictor of marriage satisfaction.

The data was analyzed using the SPSS 25.0 software package. Three standard linear regressions were run to measure how marriage satisfaction related to the differing independent variables.

Threats to Validity

This study possessed several threats to validity. One of the most important threats to validity was the use of convenience sampling. Because I used a convenience sample, my participants were not obtained by random sampling. This is a threat to validity because convenience samples have lower validity than random samples and may not be representative of the larger population (Frankfort-Nachmias & Nachmias, 2008). By collecting data from a wider range of national support groups and CHD organizations, I

attempted to enhance generalizability. Increasing generalizability adds external validity to a study, which will help balance the threat to validity that the convenience sampling may cause (Frankfort-Nachmias & Nachmias, 2008).

I expected to have a difficult time gathering participants, as parents of children with CHDs may not be open to answering questions about their marriage. Also, these parents may be apprehensive in discussing their level of stress surrounding their child with CHD. Furthermore, only one parent from each family was able to participate, which limited my participant pool.

Measuring marriage satisfaction also posed several threats to validity. For example, there are many variables that can impact marriage satisfaction beyond the scope of parental coping and stress arising from a child's illness. Financial status and financial management amongst couples has been shown to significantly impact marriage satisfaction, independent of the presence of children (Parrotta, & Johnson, 1998). In addition, negative interpersonal communication between married couples has also been explored for its propensity to impact couples' satisfaction (Feeney, Noller, & Callan, 1994). Beyond these factors, there were numerous alternate potential sources of both internal and external factors that may lead to interpersonal conflict within a married couple, impacting marriage satisfaction.

There were also threats to internal validity. Participants may have engaged in social desirability bias when they realized what the study is about. Also, asking parents of children with CHD to honestly respond about their levels of stress may have led to higher dropout rates if they became uncomfortable and chose not to complete a portion of

the surveys. Furthermore, asking these parents to respond to questions about their marriage might have reduced the number of potential participants. Both scenarios could have potentially impacted who participated in my study. Additionally, my data may have been skewed by the type of participant willing to complete the surveys, versus the type of participants that may drop out. If individuals with less parenting stress completed the scales and submitted them, and more individuals with higher parental stress dropped out, my resulting marriage satisfaction data would not be representative of the true population. Another threat to validity is being able to draw causal relationships in correlational designs (Frankfort-Nachmias & Nachmias, 2008). While findings may indicate that there are predictors of marriage satisfaction, they may only be causal variables. Another threat to validity might be other unforeseen factors that contribute to marriage satisfaction or dissatisfaction besides raising a child with CHD. While this study was focused on the variables of parental stress, parental support, and parental coping, other factors clearly relate to marriage.

Ethical Procedures

Data collection began after permission was gained from Walden University's Institutional Review Board (IRB). To gain IRB permission, I accounted for the risks and benefits of participants in the study, participation, and ensured confidentiality. In addition, for IRB permission, I gained permission from my target population. An IRB approval number of 08-06-19-0281817 was provided identifying Walden University's approval of this study. During the informed consent process, participants were explained the procedures for participation in the study, the importance of confidentiality, voluntary

nature of the study, and the risks and benefits associated with the study. They were also given a way to contact me with questions regarding the study. Raw data was stored electronically and password protected on a flash drive. This data did not contain any information that could identify any participants. Raw data will be kept for 5 years, as required by the Institutional Review Board. Participants could have withdrawn at any point during the study. If a participant experienced adverse effects from this study, the Children's Heart Foundation, with which I am affiliated, has contact information for counseling and support services that would have been disseminated to these individuals. Additionally, Walden University's participant pool has an email that could have provided support services if they were needed: participantpool@mail.waldenu.edu.

Summary

In Chapter 3, I provided an overview of the research methods and approach for this study. This overview included the research questions, type of data being collected, procedures for data collection, sampling procedures, power analysis, and ethical considerations. Additionally, the research questions, intended population, and sampling measures were discussed. Manners of participant recruitment and pertinent inclusion criteria were included. The research method was identified as quantitative, and a convenience sample of participants was utilized. Intended instruments and their psychometric properties were also discussed, including the Parenting Stress Index-4 Short Form, the Parenting Stress Index-4 Spouse/Parenting Partner Relationship Subscale, the Coping Health Inventory for Parents, and the ENRICH Marital Satisfaction Scale. A review of the reliability and validity of these questionnaires was provided.

Chapter 4 will include data collection procedures and results. Chapter 4 will conclude with answers to the research questions.

Chapter 4: Results

The purpose of this study was to analyze the relationship between parental stress, parental support, parental coping, and marriage satisfaction among parents with children with CHD. This quantitative nonexperimental study was done to assess the predictive relationships between these variables. The following research questions guided this study:

Research Question 1: To what extent does the parental distress component of parental stress, as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$1: Parental distress is not a significant predictor of marriage satisfaction.

H_a1: Parental distress is a significant predictor of marriage satisfaction.

Research Question 2: To what extent does the parent-child dysfunctional interaction component of parental stress, as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$2: Parent-child dysfunctional interaction is not a significant predictor of marriage satisfaction.

H_a2: Parent-child dysfunctional interaction is a significant predictor of marriage satisfaction.

Research Question 3: To what extent does the difficult child component of parental stress (i.e., how challenging the parent perceives the child to be), as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$3: Difficult child is not a significant predictor of marriage satisfaction.

H_a3: Difficult child is a significant predictor of marriage satisfaction.

Research Question 4: To what extent does the parental stress total score, as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$4 Parental stress is not a significant predictor of marriage satisfaction.

H_a4: Parental stress is a significant predictor of marriage satisfaction.

Research Question 5: To what extent does the spouse/parenting partner relationship component of parental support, as measured by the Parenting Stress Index-4 Long Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$5: Spouse/parenting partner relationship is not a significant predictor of marriage satisfaction.

H_a5: Spouse/parenting partner relationship is a significant predictor of marriage satisfaction.

Research Question 6: To what extent does the maintaining family integration, cooperation, and an optimistic definition of the situation component of parental coping, as measured by the Coping Health Inventory for Parents, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$6: Maintaining family integration, cooperation, and an optimistic definition is not a significant predictor of marriage satisfaction.

H_a6: Maintaining family integration, cooperation, and an optimistic definition is a significant predictor of marriage satisfaction.

Research Question 7: To what extent does the maintaining social support, self-esteem, and psychological stability component of parental coping, as measured by the Coping Health Inventory for Parents, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale (idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$7: Maintaining social support, self-esteem, and psychological stability is not a significant predictor of marriage satisfaction.

H_a7: Maintaining social support, self-esteem, and psychological stability is a significant predictor of marriage satisfaction.

Research Question 8: To what extent does the understanding the medical situation through communication with other parents and consultation with medical staff component of parental coping, as measured by the Coping Health Inventory for Parents, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale

(idealistic distortion, marital satisfaction, and total marriage satisfaction), for parents of children with CHD.

$H_0$8: Understanding the medical situation through communication with other parents and consultation with medical staff is not a significant predictor of marriage satisfaction.

H_a8: Understanding the medical situation through communication with other parents and consultation with medical staff is a significant predictor of marriage satisfaction.

Chapter 4 presents a description of the data collection, an evaluation of the statistical assumptions, and the results from the multiple regression analyses.

Data Collection

Survey data was collected from August 27, 2019 to September 2, 2020. Surveys were administered electronically via a one-time use survey link that was provided to parents who were interested in completing the survey. The survey was administered via SurveyMonkey and was promoted via social media. Links to the survey were shared on Facebook CHD parent support and charity groups. The Walden Participant Pool was not utilized for this study, as no potential respondents met the necessary criteria of raising a child with a CHD. A total of 249 participants responded to this study. Six of these did not meet inclusion criteria. Of all responses, 37 of these were incomplete, as these respondents withdrew without completing all the survey questions. After removal of these incomplete responses, a final sample size of 206 respondents was included in the

final analyses. Response rate could not truly be calculated, due to not knowing the number of eligible individuals belonging to those social groups.

Results

Descriptive statistics for the sample and results of the regression analyses are presented in this section. Means and standard deviations were calculated, as well as frequencies and percentages for the categorical variables. Multiple linear regression was conducted for parental stress, parental support, and parental coping as potential predictors of marriage satisfaction.

Descriptive Statistics

Participants responded to screening questions prior to accessing the survey questions. All participants reported that they were biological parents of a child with a CHD (n = 206, 100%). They also reported that English was their primary language (n = 206, 100%) for the purposes of proper survey administration. Participants also reported that they currently had custody of that child, and that they currently lived with and were married to their spouse (n = 206, 100%). These indicated that all the respondents met the inclusionary criteria for the study. Parents were asked to report demographic information regarding their age, gender, educational background, ethnicity, annual income, and marriage length. Many participants reported that they were between the ages of 35 and 44 (n = 86, 48%). Most participants indicated that they were female (n = 137, 66%). For education, most participants reported that they had a college degree (n = 123, 60%). The sample was diverse in terms of race and ethnicity, with White being the most common (n = 114, 55%). There were also fairly even proportions reported for participant annual

income and years married to spouse. Demographic characteristics for participants are presented in Table 1.

Table 1

Frequency Table for Parent Demographic Characteristics

Variable	*n*	*%*
Age		
18 to 24	6	3
25 to 34	51	25
35 to 44	86	48
45 to 54	55	27
55 to 64	8	4
Gender		
Female	137	66
Male	69	33
Highest Level of Education		
High School Diploma	23	11
College Degree	123	60
Graduate Degree	60	29
Ethnicity		
Asian	17	8
Black/African American	25	12
Hispanic/Latino	18	9
Mixed Ethnicity	27	13
White	114	55
Other	4	2
Average Annual Income		
$30,000 or less	2	1
$31,000- $50,000	27	13
$51,000-$70,000	89	43
$71,000-$90,000	48	23
$91,000 or more	40	19
Years Married to Spouse		
1-5 years	72	35
6-10 years	89	43
11 years or longer	44	21

Note. Due to rounding errors, percentages may not equal 100%.

Parents were also asked to report information pertaining to their child with CHD. These items included: child's current age, which CHD was diagnosed, age at time of diagnosis, and number of total children in the household. Children's ages ranged from newborn to 26 years. The mean age of children in the sample was 4.71 years. Most children had been diagnosed with their disability either during pregnancy or before 2 years old (n = 191, 93%). The most common disability diagnosis for children in the sample was ASD/VSD (n = 56, 27%). The most common number of children in each household was two (n = 90, 44%). Frequencies and percentages for characteristics of children are presented in Table 2.

Table 2

Frequency Table for Characteristics of Children

Variable	*n*	*%*
Child Primary Diagnosis/Disability		
Tetralogy of Fallot	31	15
Transposition of Great Arteries	29	14
Hypoplastic left/right Heart Syndrome	54	26
ASD/VSD	56	27
Other	36	18
Age of Child		
1 month old-11 months old	4	2
12 months old-23 months old	15	7
2 years old-4 years old	96	47
5 years old-6 years old	33	16
7 years old-10 years old	35	17
11 years old and older	23	11
Child's Initial Age of Diagnosis		
During Pregnancy	84	41
Birth-1 years old	107	52
2 years old or older	15	7
Number of Children in the Home		
1	65	32
2	90	44
3	39	19
4 or more	11	5

Note. Due to rounding errors, percentages may not equal 100%.

The means and standard deviations for parental stress (PSI-4 SF Stress), parental support (PSI-4 LF), parental coping (CHIP Coping), and marital satisfaction (ENRICH Marital Satisfaction) and the associated subscales are shown in Table 3. The mean total parental stress score was 103.33 (*SD* = 13.49). Of the stress subscales, parents scored highest on parental distress with an average of 35.35 (*SD* = 6.20) and range of 12.00 to

56.00. For parental support, the mean score on the Spouse/Parenting Partner Relationship subscale was 20.81 (*SD* = 4.48). In the area of parental coping, parents scored highest on the Maintaining Family Integration subscale (M=31.72, *SD* = 7.42) with a range of 12.00 to 55.00. The mean score for total marriage satisfaction was 42.80 (*SD* = 15.24) with a range of scores from 9.00 to 86.00.

Table 3

Descriptive Statistics for Parental Stress, Parental Support, Parental Coping, and Marriage Satisfaction

Variable	*M*	*SD*	*n*	Min.	Max.
PSI-4 SF Stress					
Parental Distress	35.35	6.20	206	12.00	56.00
Parent-Child Dysfunctional Interaction	33.88	6.19	206	16.00	48.00
Difficult Child	34.09	5.52	206	17.00	45.00
Total Stress Score	103.33	13.49	206	47.00	145.00
PSI-4 LF					
Spouse/Parenting Partner Relationship	20.81	4.48	206	7.00	33.00
Coping Health Inventory					
Maintaining Family Integration	31.72	7.42	206	12.00	55.00
Maintaining Social Support	28.83	7.03	206	10.00	54.00
Understanding the Healthcare Situation	12.51	3.72	206	3.00	24.00
Enrich Marital Satisfaction					
Idealistic Distortion	13.61	4.17	206	5.00	24.00
Marital Satisfaction	30.73	5.35	206	14.00	48.00
Total Marriage Satisfaction	42.80	15.24	206	9.00	86.00

Evaluation of Statistical Assumptions

Prior to conducting the multiple linear regression analyses, I assessed the assumptions of normality, homoscedasticity, and multicollinearity. I compared the calculated values for skewness and kurtosis to the established guidelines to indicate that the data distribution would differ from a normal distribution. The critical values were ±2 for skewness and ±3 for kurtosis (Westfall & Henning, 2013). When the skewness is greater than or equal to 2 or less than or equal to -2, then the variable is considered to be asymmetrical to its mean. When the kurtosis is greater than or equal to 3, then the variable's distribution is significantly different from a normal distribution in its tendency to produce outliers (Westfall & Henning, 2013). The Shapiro-Wilk test was conducted to test for normality. The total stress score exceeded the parameters of kurtosis with a value of 4.83, and therefore was not normally distributed. Besides this score, all other scores met parameters and were normally distributed. As a result, the assumption of normality was mostly met.

Table 4

Results of the Normality Testing for Parental Stress, Parental Support, Parental Coping and Marriage Satisfaction

Variable	Statistic	*df*	*p*	Skewness	Kurtosis
PSI-4 SF Stress					
Parental Distress	.948	206	0.00	-.537	2.77
Parent Child Dysfunctional Interaction	.949	206	0.00	-.767	1.14
Difficult Child	.961	206	0.00	-.732	.445
Total Stress Score	.876	206	0.00	-1.48	4.83
PSI-4 LF					
Spouse/Parenting Partner Relationship	.972	206	0.00	-.390	.872
Coping Health Inventory					
Maintaining Family Integration	.954	206	0.00	.758	1.08
Maintaining Social Support	.913	206	0.00	1.15	1.18
Understanding the Healthcare Situation	.984	206	0.02	.346	067
Enrich Marital Satisfaction					
Idealistic Distortion	.971	206	0.00	.315	-.677
Marital Satisfaction	.979	206	0.03	.117	1.18
Total Marriage Satisfaction	.993	206	0.46	.003	-.307

To assess homoscedasticity, I examined a residual scatterplot for the predicted versus standardized data. The points appeared to be distributed about a mean value of zero and there was no curvature in the plots. Therefore, the assumption of homoscedasticity was met. Figures 1, 2, and 3 present the residual scatterplot for homoscedasticity.

Figure 1

Residuals Scatterplot for Homoscedasticity- Idealistic Distortion

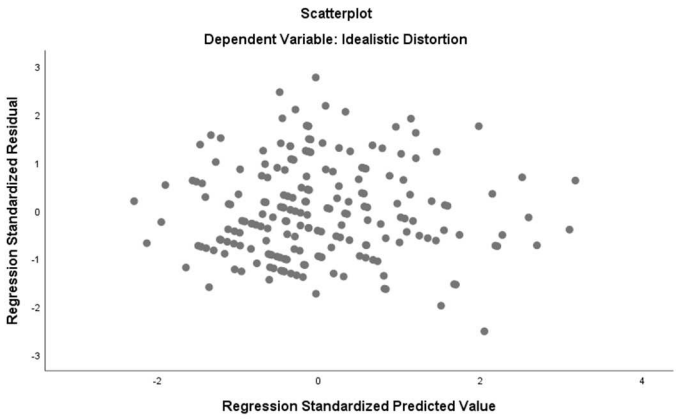


Figure 2

Residuals Scatterplot for Homoscedasticity- Marital Satisfaction

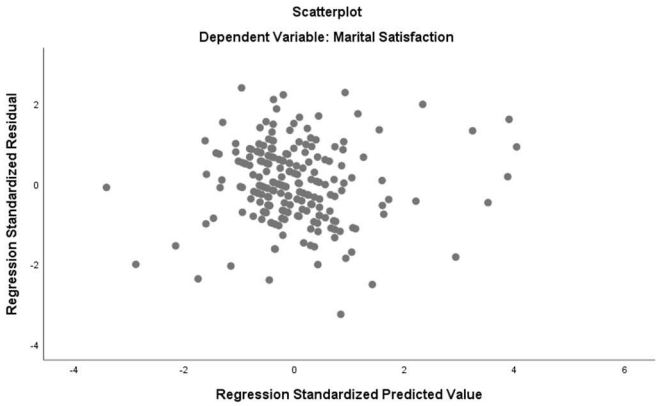
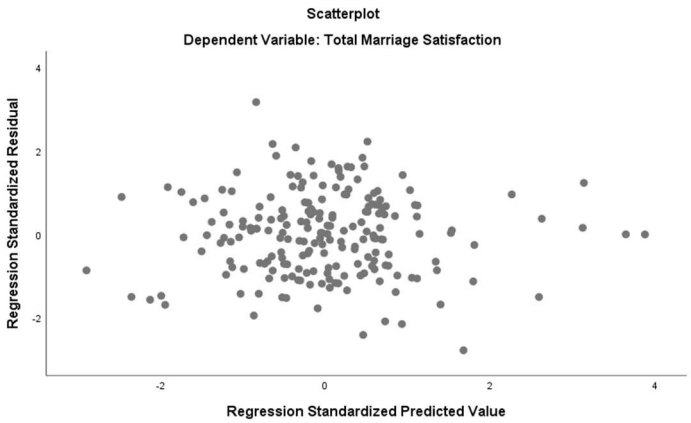


Figure 3

Residuals Scatterplot for Homoscedasticity- Total Marriage Satisfaction



Multicollinearity was assessed by examining the Variance Inflation Factors (VIFs) for the predictor variables. The VIFs were examined where values greater than five may indicate issues while values greater than 10 are considered evidence of multicollinearity. Table 5 presents the VIF values for the predictor variables. The data suggests that the predictor variables are not highly correlated. The multicollinearity assumption was met, as VIF values are well below 10 and tolerance scores are above 0.2.

Table 5

Collinearity Diagnostics for the Predictor Variables

Variable	Tolerance	VIF
Parental Distress	.766	1.31
Parent-Child Dysfunctional Interaction	.659	1.52
Difficult Child	.660	1.52
Spouse/Parenting Partner Relationship	.803	1.25
Maintaining Family Integration	.486	2.08
Maintaining Social Support	.501	1.99
Understanding the Healthcare Situation	.644	1.55

In addition to testing the assumptions for multiple regression, Cronbach's alpha was computed to test the internal consistency of the instruments used for the current sample. Table 6 provides the Cronbach's alpha coefficients (*a*) for each instrument/subscale. Each had acceptable internal consistency, ranging from .61 to .87.

Table 6

Cronbach's Alpha Coefficients for Study Instruments

Variable	α
Parental Distress	.871
Parent-Child Dysfunctional Interaction	.853
Difficult Child	.652
Spouse/Parenting Partner Relationship	.793
Maintaining Family Integration	.691
Maintaining Social Support	.673
Understanding the Healthcare Situation	.605
Idealistic Distortion	.697
Marital Satisfaction	.804
Total Marriage Satisfaction	.812

Multiple Regression Analyses

To address the research questions guiding this study I conducted multiple linear regression analyses using the standard entry method. The standard method allowed the addition of the predictor variables and demographic variables into the regression model one at a time. The predictor variables from the research questions were parental stress (the parental distress, parent-child dysfunctional interaction, difficult child, and total stress subscales from the PSI-4 SF), parental support (the spouse/parenting partner relationship subscale of the PSI-4 LF), and parental coping (the maintaining family integration, maintaining social support, and understanding the healthcare situation

subscales from the CHIP). I conducted a total of three standard multiple linear regression analyses, one for each of the two subscales of the ENRICH Marital Satisfaction Scale, and one for a total marriage satisfaction score.

Multiple Regression: Predicting Marriage Satisfaction (Idealistic Distortion)

I conducted a multiple linear regression analysis to assess the relationship between the predictor variables and idealistic distortion. The Idealistic Distortion subscale assesses the tendency for individuals to respond to statements in a socially desirable manner. It measures the extent to which a person distorts their relationship in a positive direction (Fowers & Olson, 1993). Idealistic distortion is scored in a negative direction and is used to adjust the scores of the marital satisfaction subscale in a downward direction (Fowers et al., 1992b). The predictor variables for the multiple linear regression were parental distress, parent-child dysfunctional interaction, difficult child, spouse/parenting partner relationship, maintaining family integration, maintaining social support, and understanding the healthcare situation.

The result of the multiple linear regression was statistically significant, $F(7,206) = 7.40$, $p < .001$, $R^2 = 0.21$. This finding indicated that the model provided a statistically significant contribution to the variance in idealistic distortion. Specifically, the model accounted for 21% of the variation in idealistic distortion.

The difficult child subscale of parental stress was a statistically significant predictor of idealistic distortion, $B = -0.17$, $p = .004$. The results indicated that as difficult child scores increased, idealistic distortion scores decreased. On average, for every one-unit increase in difficult child, there was a 0.17 unit decrease in idealistic

distortion. The spouse/parenting partner relationship subscale of parental support was a statistically significant predictor of idealistic distortion, $B = -0.28$, $p < .001$. The results indicated that as spouse/parenting partner relationship scores increased, idealistic distortion scores decreased. On average, for every one-unit increase in spouse/parenting partner relationship, there was a 0.28 unit decrease in idealistic distortion. The maintaining social support subscale of parental coping was a statistically significant predictor of idealistic distortion, $B = 0.11$, $p = .035$. The results indicated that as maintaining social support scores increased, idealistic distortion scores increased. On average, for every one-unit increase in maintaining social support, there was a 0.11 unit increase in idealistic distortion.

The remaining scales of parental distress, parent/child dysfunctional interaction, maintaining family integration, and understanding the healthcare situation were not statistically significant predictors of idealistic distortion. Table 7 presents the results for the individual predictors.

Table 7

Results of the Multiple Linear Regression Predicting Idealistic Distortion

Variable	*B*	*SE*	β	*t*	*p*
Parental Distress	.082	.049.	122	1.67	.093
Parent-Child Dysfunctional Interaction	.033	.053	.050	.637	.525
Difficult Child	-.171	.059	-.227	-2.91	.004
Spouse/Parenting Partner Relationship	-.279	.066	-.299	-4.24	.000
Maintaining Family Integration	-0.94	.051	-.167	-1.84	.067
Maintaining Social Support	.113	.053	.190	2.12	.035
Understanding the Healthcare Situation	.159	.088	.142	1.80	.073

Note. $F(7,206) = 7.40$, $p < .001$, $R^2 = 0.21$.

Multiple Regression: Predicting Marriage Satisfaction (Marital Satisfaction Subscale)

I conducted a multiple linear regression analysis to assess the relationship between the predictor variables and marital satisfaction. The marital satisfaction subscale represents 10 areas of the marital relationship assessed to be most important by Fournier et al. (1983) (e.g., communication, sexual relationship). The predictor variables for the multiple linear regression were parental distress, parent-child dysfunctional interaction, difficult child, spouse/parenting partner relationship, maintaining family integration, maintaining social support, and understanding the healthcare situation.

The result of the multiple linear regression was statistically significant, $F(7,206) = 7.34$, $p < .001$, $R^2 = 0.21$. This finding indicated that the model provided a statistically significant contribution to the variance in marital satisfaction. Specifically, the model accounted for 21% of the variation in marital satisfaction score.

The parent/child dysfunctional interaction subscale of parental stress was a statistically significant predictor of marital satisfaction, $B = -0.19$, $p = .006$. The results indicated that as parent/child dysfunctional interaction scores increased, marital satisfaction scores decreased. On average, for every one-unit increase in parent/child dysfunctional interaction, there was a 0.19 unit decrease in marital satisfaction. The spouse/parenting partner relationship subscale of parental support was a statistically significant predictor of marital satisfaction, $B = -0.37$, $p < .001$. The results indicated that as spouse/parenting partner relationship scores increased, marital satisfaction scores

decreased. On average, for every one-unit increase in spouse/parenting partner relationship, there was a 0.37 unit decrease in marital satisfaction.

The remaining scales of parental distress, difficult child, maintaining family integration, maintaining social support, and understanding the healthcare situation were not statistically significant predictors of marital satisfaction. Table 8 presents the results for the individual predictors.

Table 8

Results of the Multiple Linear Regression Predicting Marital Satisfaction

Variable	*B*	*SE*	β	*t*	*p*
Parental Distress	-.088	.062	-.102	-1.42	.158
Parent-Child Dysfunctional Interaction	-.188	.067	-.217	-2.78	.006
Difficult Child	.021	.076	.022	.277	.782
Spouse/Parenting Partner Relationship	-.367	.084	-.307	-4.35	.000
Maintaining Family Integration	-.003	.065	-.005	-.051	.959
Maintaining Social Support	.040	.068	.052	.582	.561
Understanding the Healthcare Situation	-.023	.114	-.016	-.205	.838

Note. $F(7,206) = 7.34$, $p < .001$, $R^2 = 0.21$.

Multiple Regression: Predicting Marriage Satisfaction (Total Marriage Satisfaction)

I conducted a multiple linear regression analysis to assess the relationship between the predictor variables and total marriage satisfaction. The predictor variables for the multiple linear regression were parental distress, parent-child dysfunctional interaction, difficult child, spouse/parenting partner relationship, maintaining family integration, maintaining social support, and understanding the healthcare situation.

The result of the multiple linear regression was statistically significant, $F(7,206) = 2.65$, $p < .001$, $R^2 = .086$. This finding indicated that the model provided a statistically

significant contribution to the variance in total marriage satisfaction. Specifically, the model accounted for 8.6% of the variation in total marriage satisfaction score.

The parent/child dysfunctional interaction subscale of parental stress was a statistically significant predictor of total marriage satisfaction, $B = -0.55$, $p = .008$. The results indicated that as parent/child dysfunctional interaction scores increased, total marriage satisfaction scores decreased. On average, for every one-unit increase in parent/child dysfunctional interaction, there was a 0.55 unit increase in total marriage satisfaction. The spouse/parenting partner relationship subscale of parental support was also a statistically significant predictor of total marriage satisfaction, $B = -0.50$, $p = .043$. The results indicated that as spouse/parenting partner relationship scores increased, total marriage satisfaction scores decreased. On average, for every one-unit increase in spouse/parenting partner relationship, there was a 0.50 unit decrease in total marriage satisfaction.

The remaining scales of parental distress, difficult child, maintaining family integration, maintaining social support, and understanding the healthcare situation were not statistically significant predictors of total marriage satisfaction score. Table 9 presents the results for the individual predictors.

Table 9

Results of the Multiple Linear Regression Predicting Total Marriage Satisfaction

Variable	*B*	*SE*	β	*t*	*p*
Parental Distress	-.306	.191	-.125	-1.61	.110
Parent-Child Dysfunctional Interaction	-.551	.206	-.224	-2.67	.008
Difficult Child	.354	.231	.128	1.53	.127
Spouse/Parenting Partner Relationship	-.503	.258	-.148	-1.95	.043
Maintaining Family Integration	.117	.200	.057	.585	.559
Maintaining Social Support	-.077	.208	-.036	-.370	.712
Understanding the Healthcare Situation	-.364	.347	-.089	-1.05	.296

Note. $F(7,206) = 2.65$, $p < .001$, $R^2 = .086$.

Summary

I investigated the predictive relationship of marriage satisfaction to parental stress (parental distress, parent-child dysfunctional interaction, difficult child, and total stress), parental support (spouse/parenting partner relationship), and parental coping (maintaining family integration, maintaining social support, and understanding the healthcare situation). I conducted multiple linear regression analyses to determine if there was a statistically significant relationship between the predictor variables and criterion variables. A regression analysis was conducted for each of the two subscales of the ENRICH Marital Satisfaction Scale, as well as for the total marriage satisfaction score.

Parent/child dysfunctional interaction was a statistically significant predictor of the marital satisfaction subscale and total marriage satisfaction. Difficult child was a statistically significant predictor of idealistic distortion. Spouse/parenting partner relationship was a statistically significant predictor of idealistic distortion, marital satisfaction, and total marriage satisfaction. Maintaining social support was a statistically significant predictor of idealistic distortion. Finally, parental distress, maintaining family

integration, and understanding the healthcare situation were not statistically significant predictors for any of the measures of marriage satisfaction. In Chapter 5, an interpretation of the findings, the limitations of the study, and recommendations for future research will be presented.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this quantitative study was to determine what impact different aspects of parental stress, parental support, and parental coping have on the marriage satisfaction of parents raising a child with a CHD. Children diagnosed with CHD often require specialized care, surgical intervention, and a myriad of additional supports. For the parents of children with CHD, previous research has established that caring for their child is associated with higher perceived levels of stress as compared to the parents of children without CHD (Rassart, 2013). Studies exploring the sources of stress for parents of children with CHD have found that uncertain future health, additional financial burdens, and comorbid child behavior challenges added to perceived parental stress (Nadeem et al., 2016; Soulvie et al., 2012). Positive coping skills have also been associated with mitigating parental stress when caring for sick children (Bratt et al., 2015). Additionally, research has found that higher levels of stress within any couples' relationship can negatively impact overall marriage satisfaction (Randall & Bodenmann, 2017). Prior research has not addressed the relationship between parental stress, parental support, parental coping, and marriage satisfaction within parents of children with CHD.

The data for this study was analyzed using standard multiple linear regression analyses. The results of this study identified parent/child dysfunctional interaction as a statistically significant predictor of marital satisfaction and total marriage satisfaction. The variable "difficult child" was a statistically significant predictor of idealistic distortion. Spouse/parenting partner relationship was a statistically significant predictor of idealistic distortion, marital satisfaction, and total marriage satisfaction. Maintaining

social support was a statistically significant predictor of idealistic distortion. Finally, parental distress, maintaining family integration, and understanding the healthcare situation were not statistically significant predictors for any of the measures of marriage satisfaction.

In this chapter, I discuss in greater detail the findings of this research study in the interpretation of findings section. I also address the limitations of this study, followed by recommendations for future research and implications for social change. The chapter ends with conclusions for this study.

Interpretation of the Findings

Parental Stress

Research Questions 1 through 4 asked to what extent does the parental distress (RQ1), parent-child dysfunctional interaction (RQ2), difficult child (RQ3), and total stress (RQ4) components of parental stress, as measured by the Parenting Stress Index-Short Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale, for parents of children with CHD.

Prior research has indicated that raising a child with complex medical needs, such as a congenital heart defect, can often lead to stress (Soulvie et al, 2012). Parental stress can arise from a multitude of different sources, and it can vary widely depending upon the lived experiences of caring for a child, as well as the child's well-being. For the parents of a child with a disability, levels of perceived health can significantly impact parental stress (Nadeem, et al., 2016). Parents raising a child with a chronic illness, such

as CHD, have also reported significantly higher levels of parental stress than the parents of healthy children (Miodrag et al., 2015).

Parenting stress can also arise due to cognitive and developmental concerns with their children (Gupta, 2007). Diagnoses such as ADHD and anxiety have increasingly been seen within children with CHD (Demaso et al., 2017). Such neurocognitive deficits that can impact cognitive functioning occur as a side effect of surgical bypass, which restricts oxygen to the brain during corrective procedures (Sterken et al., 2016). The higher psychiatric comorbidity and cognitive challenges of ADHD among children with CHD can also impact levels of parental stress (Demaso et al., 2017).

Previous research has identified that the psychological stress placed upon parents of children with CHD arises from the emotional stress of their child's cardiac illness (Hearps et al., 2014). In many cases of CHDs, complex surgery and palliative care become necessary. Whether prenatally or prior to surgical intervention during infancy, the shock of learning about their child's heart malformation has significant impacts on parental stress (Vrijmoet-Wiersma et al., 2009). Research conducted by Doherty et al. (2009) has shown that feelings of helplessness and vulnerability add to perceived stress, as CHD parents deal with a desire to understand the diagnosis and reconcile their healthcare choices. Likewise, research has ascertained that parental stress, both before and after surgery, lingered due to ongoing acceptance of their child (Uzark & Jones, 2003). Uzark and Jones (2003) and Hearps et al. (2014) suggested that a child with CHD may not match the expectations of the parents, which could lead to feelings of guilt and long-term stress.

From a relationship perspective, stress can have a substantial impact on marriage satisfaction. Randall and Bodenmann (2017) elaborated upon Bodenmann's stress-divorce model (1995) by addressing how everyday stressors can influence relationship functioning. More specifically, they detailed how the negative association between stress and relationship satisfaction is a dyadic construct, which means that successfully addressing relationship satisfaction needs to arise from honing into the specific source of stress that is present (such as financial, partner illness, difficult child, and so on; Randall & Bodenmann, 2017). For couples raising a child with a disability, marriage/relationship satisfaction can be negatively affected compared to the normal population (Hatton et al., 2010). A child's disability may add to perceived levels of parental stress (stress, anxiety, and depression) and contribute to fragments within the familial dynamic (Hatton et al., 2010). When applied to parents of children with CHD, parental stress, anxiety, and depression were common after prenatal diagnoses were discovered (Rychik et al., 2013). It has been theorized that positive partner relationships and stronger social support networks can mitigate these emergent emotional issues (Rychik et al., 2013; Werner et al., 2014).

The results of the current study demonstrated that parenting stress was a significant predictor of marriage satisfaction in the areas of parent/child dysfunctional interaction and difficult child. Parent/child dysfunctional interaction was a statistically significant predictor of marriage satisfaction. As parent/child dysfunctional interaction scores increased, marriage satisfaction scores decreased. This suggests that the more dysfunction that a parent perceives in their interactions with their child, the less

satisfaction they have in their marriage. This aligns with previous research, which demonstrated that a lack of established bond/satisfaction between parent and child may lead to disharmony in other relationships (e.g., Johnson et al., 1986; Robinson & Neece, 2015). The difficult child component of parental stress was a statistically significant predictor of idealistic distortion. As difficult child scores increased, idealistic distortion scores decreased. This suggests that the more challenging that parents perceived their child to be, the less likely the parent was to respond to statements in a socially desirable manner. That is, the more difficult that parents perceived their child to be, the more likely that the parents had a more realistic view of relationship satisfaction and were more likely to discuss problems with their spouse. Fowers et al. (1992) states that an individual with such a realistic relationship viewpoint tends to feel that their feelings/concerns are minimized by their partner. Therefore, it is possible that respondents reporting higher scores in difficult child and lower scores in idealistic distortion feel dismissed/marginalized by their partner when discussing their child's behavior. This seems to align with previous research, which found that parents dealing with high levels of spouse or child challenges were less likely to engage in marital conventionalization or idealistic distortion (Fowers et al., 1992).

The parental distress subscale of parental stress was not a significant predictor of marriage satisfaction. The parental distress subscale measured the stresses associated with restricted life-roles, emotional adjustment challenges, and a lack of social support. Abidin (2012) stated that individuals scoring highly in the parental distress subscale have significant challenges to their personal adjustment to being a parent. For example, a

mother diagnosed with postpartum depression may score highly on the parental distress subscale (Abidin, 2012). The subscale's lack of significance to marriage satisfaction in this study may be attributed to personal adjustment challenges generally not being present amongst this group of participants.

Parental Support

Research Question 5 asked to what extent does the spouse/parenting partner relationship component of parental support, as measured by the Parenting Stress Index-4 Long Form, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale, for parents of children with CHD.

Prior research has indicated that raising a child with complex medical needs and/or disabilities can cause high levels of parental stress when there is a lack of social/emotional supports (Nadeem et al., 2016). Mörelius and Hemmingsson (2014) asserted that perceived lack of societal and financial support by parents when caring for their sick children significantly correlated with higher levels of parental stress. Conversely, research has shown that the availability of emotional support from one's partner when raising a child with congenital heart defect was the only mitigating factor in decreasing parental stress (Solberg et al., 2012). Bratt et al. (2015) concluded that the support and education from the medical community, in conjunction with partner support, directly aided a parent's ability to cope with their child's diagnosis of CHD.

Additional studies have concluded that bolstering parental support through support groups and education enhances positive communication amongst couples (Burke et al., 2014). Berant et al. (2003) contended that marriage satisfaction is determined by

availability of emotional support and stability, rather than the child's CHD diagnosis alone. It has been suggested that poor communication, role incongruity, and lack of intimacy can cause marital dissatisfaction within the CHD parent population (Berant et al., 2003).

The results of this study demonstrated that the spouse/parenting partner relationship component of parental support was a significant predictor of each aspect of marriage satisfaction. Spouse/parenting partner relationship component of parental support was a statistically significant predictor of idealistic distortion, marital satisfaction, and total marriage satisfaction. As the spouse/parenting partner relationship component of parental support scores increased, scores in idealistic distortion, marital satisfaction and total marriage satisfaction decreased. Parents who receive high scores on the spouse/parenting partner relationship scale lack the emotional and active support of the other parent in the areas of child management and emotional support (Abidin, 2012). The most likely reason for high scores on this scale is a general negative relationship between partners. Therefore, the less emotional and active support of one's partner, the more likely they reported lower levels of marriage satisfaction. Similarly, the less emotional and active support of one's partner, the less likely participants were to paint their relationship with their partner in a positive light on the idealistic distortion scale. This could suggest why, as parental support scores decrease, participants are less likely to distort their relationship in a positive manner.

These findings align with previous research, as other studies have suggested that the presence of emotional support from one's partner can lead to an increased ability to

adapt to the stresses of parenting a child with CHD (Bruce, Lilja, & Sundin, 2014). In turn, such perceived support could lead to more favorable perceptions of marriage satisfaction. Werner et al. (2014) asserted that a parent's ability to navigate the coping phases and cognitive appraisals of caring for a sick child can either be aided dramatically or diminished by their perceptions on marriage satisfaction.

Parental Coping

Research Questions 6 through 8 asked to what extent does maintaining family integration, cooperation, and an optimistic definition of the situation (RQ6), maintaining social support, self-esteem, and psychological stability (RQ7), and understanding the medical situation through communication with other parents and consultation with medical staff (RQ8), components of parental coping, as measured by the Coping Health Inventory for Parents, relate to marriage satisfaction, as measured by the ENRICH Marital Satisfaction Scale, for parents of children with CHD.

Prior research has indicated that parental stress when raising a child with a congenital heart defect was directly related to either an ability or inability to cope with diagnosis and treatment (Leon, Wallenberg, & Holliker, 2013). Acknowledging the importance of social support and education is significantly related to properly coping and minimizing parental stress. For example, Bratt et al. (2015) found that parents' ability to cope effectively with their child's diagnosis was significantly heightened by medical staff increasing their knowledge and understanding of CHD. Having medical staff educate parents about CHD aided significantly in parents feeling supported (Bratt et al., 2015).

Another prominent factor that can significantly impact parental coping is the presence or absence of psychosocial support from one's partner (Werner et al., 2014). Additionally, a parent's ability to navigate the coping phases and cognitive appraisals of their child's diagnosis can either be aided dramatically or diminished by their perceptions on marriage satisfaction. Leon, Wallenberg, and Holliker (2013) indicated that a preexisting strong marital satisfaction can serve as a positive source of coping when facing a child with a CHD diagnosis. They found that there was a significant relationship between partner satisfaction, positive coping, and the use of emotional social support (Leon et al., 2013). It was suggested that although individual coping skills are important, partner satisfaction may be a better predictor of parental resilience when facing a prenatal CHD diagnosis (Leon et al., 2013).

The results of this study demonstrated that the subscale of maintaining social support, self-esteem, and psychological stability was a statistically significant predictor of marriage satisfaction in the area of idealistic distortion. As scores on this scale increased, idealistic distortion scores also increased. Parents with high scores in maintaining social support, self-esteem, and psychological stability typically place a lot of effort into developing relationships with others. They engage in activities to enhance feelings of self-worth, as well as behaviors to manage psychological pressures (McCubbin et al., 1983). This seems to align with high scores on the idealistic distortion scale, as high scores on the idealistic distortion scale typically denote a person that presents their relationships in a highly favorable manner. These individuals may also resist

acknowledging and discussing the problematic areas of their relationships (Fowers & Olson, 1989).

These findings align with previous research, as Rychik et al. (2013) found that higher levels of acceptance of CHD, as well as higher levels of positive reinterpretation (seeing the positive side of things), were associated with decreased amounts of parental anxiety. A parent's ability to come to terms with a diagnosis of CHD and seek positive solutions significantly impacted their ability to alleviate parental stress (Rychik et al., 2013). Acknowledging the importance of social support and education appears significant to properly coping and minimizing parental stress. Studies have also concluded that the ongoing existence of emotional support has bolstered parental confidence/ability to cope (Ahn et al., 2014; Burke et al., 2014). Werner et al. (2014) acknowledged that psychosocial support from one's partner plays a prominent role in impacting parental coping. Aspiring to maintain a positive and supportive marriage was seen to be of key importance amongst parents coping with a child with CHD (Ahn et al., 2014).

The parental coping subscales of maintaining family integration, cooperation, and an optimistic definition of the situation (RQ6), and understanding the medical situation through communication with other parents and consultation with medical staff (RQ8) were not statistically significant predictors of marriage satisfaction across all three scales of the dependent variable. This finding may simply be due to these areas of parental coping not playing a prominent role in marriage satisfaction. These findings do align with previous research, as families of chronically ill children might seek to restore emotional balance and promote well-being in response to stress (Dale et al., 2013). Furthermore,

family functioning and parental separation/divorce rates among couples caring for a child with CHD were found to be at no higher risk for separation/divorce than parents of children without CHD after two years of age (Brenner et al., 2016).

Theoretical Framework and Research Findings

The theoretical framework for this study was Minuchin's structural family theory (Minuchin, 1974). Structural family theory was developed by Minuchin as a way to explain how an individual's challenges can contribute to a dysfunctional family system. This theory asserts that stressors on the family, such as raising a chronically ill or disabled child, can influence the emotional functioning of members of that family. Structural family theory views the family dynamic as a social group that influences and is influenced by social contexts (Minuchin, 1974). These social contexts can be either internal or external. An example of this is a child's behavior or health concerns having a direct impact upon their parent's levels of stress.

Minuchin's structural family theory has been applied to previous research focused on stress and the health of the family. Vetere (2001) contended that structural family theory could be applied to stress and conflict in couples, childhood behavior challenges, and chronic physical illness in children. Regarding chronic childhood illness, Minuchin (1974) contended that the family is a system. As part of that system, interpersonal patterns within a family interact with individual biological functioning, including illnesses. Since one's functioning can be impacted by interpersonal patterns of interaction, Minuchin's structural family theory is applicable to both stress and conflict in couples when raising a chronically ill child.

This model was the basis for this study because it identifies how dysfunction in the family dynamic arises due to internal or external burdens (Minuchin, 1974). The stressful burden of raising a chronically ill child with CHD can impact family functioning (Miodrag et al., 2015). When the perceived roles and subsystems of the family are disrupted by a CHD diagnosis, Minuchin's explanation of the emergence of a dysfunctional family system could explain why levels of coping and marriage satisfaction become affected.

The results of this study aligned with this assumption and with Minuchin's theory. The subscales of parent/child dysfunctional interaction, difficult child, spouse/parenting partner relationship, and maintaining social support, self-esteem, and psychological stability were all predictors of certain subscales of marriage satisfaction. According to Minuchin's theory, the internal burdens and dysfunction created by needing to care for a child with CHD could lead to a decrease in marriage satisfaction. This theory is supported by the results of the current study which showed that subscales of parent/child dysfunctional interaction, difficult child, and spouse/parenting partner relationship were significant predictors of marriage satisfaction. Higher scores on the subscales of difficult child and parent/child dysfunctional interaction resulted in significantly lower scores of marriage satisfaction.

Moreover, as scores on one of the parental coping subscales (maintaining social support, self-esteem, and psychological stability) increased, scores on the marriage satisfaction subscale of idealistic distortion also increased. The subscale maintaining social support, self-esteem, and psychological stability is defined as a parent's efforts to

seek and maintain relationships with others, engage in activities which enhance feelings of individual identity and self-worth, plus behaviors to manage psychological tensions and pressures (McCubbin et al., 1983). Parents who sought to maintain these supports and engage in activities to enhance their identity/self-worth were also more likely to report their relationship in a highly favorable manner. This also aligns with Minuchin's structural family theory, as Minuchin asserted that the family structure is defined by the recognized rules and individual roles that guide the family. These systems that are developed establish boundaries for the family and lead to advanced patterns for interpersonal interaction and communication (Minuchin, 1974). Therefore, as a parent increasingly seeks to maintain social support, self-esteem, and psychological stability, they may also convey an increasing desire to paint their relationship with their partner in a positive light. Unexpectedly, the parental coping subscales of maintaining family integration, cooperation, and an optimistic definition of the situation, and understanding the medical situation through communication with other parents and consultation with medical staff were not significant predictors of any aspect of marital satisfaction. These subscales seem to align in a similar fashion to the maintaining social support, self-esteem, and psychological stability subscale. However, it is possible that the survey items related to these scales simply did not matter as much to the participants' cognitive appraisal or marriage satisfaction.

Limitations of the Study

There were several limitations to this study. One limitation was the manner of recruitment. Since convenience sampling was utilized for this study, participants were not

obtained by random sampling. This limits the generalizability of the results (Creswell, 2014). By recruiting participants from mostly local support groups and organizations, the study's results may not be representative of the whole national CHD community. Though some demographic diversity did exist in the sample, there were areas that lacked variability. These included parent ethnicity, gender, education level, and age of child. Only 33% of the respondents were male, which limited the generalizability of the research findings from the father/husband perspective. In addition, 55% of the respondents were Caucasian/white, which is a disproportionately large percentage. This also somewhat limits the generalizability to other ethnic groups such as blacks and Hispanics. Moreover, 89% of respondents had a college education level or higher. This limits the generalizability of the research findings to individuals with lower levels of education.

Furthermore, only 13% of participants responded that their child was over 10 years old. This also limits generalizability of the research findings for parents caring for older children with CHD, as well as marriage satisfaction information when raising an older child. Other limitations of this research were that participants must be English-speaking and must have been at least 18 years of age. These differing populations, while not the focus of this study, would potentially present with different stressors and aspects of marriage satisfaction that may be studied in the future (e.g., Randall & Bodenmann, 2017).

Response bias may also have been a limitation of this study (Creswell, 2014). The methodology used for this research was a survey design, which allows participants to

self-report. As a result, there is no way to determine if participants responded honestly to the survey items, or if they responded in a manner to appear more favorable and socially desirable. However, the idealistic distortion subscale of the dependent variable did measure a certain propensity to respond to marriage satisfaction questions in an overly favorable manner, and scores for this variable were found to be normally distributed (and no outliers). Similarly, normality was determined by using Q-Q plots and the Shapiro-Wilk test for all scores. The total stress score exceeded the parameters of kurtosis with a value of 4.83, and therefore was not normally distributed. Besides this score, all other scores met parameters and were normally distributed. As a result, the assumption of normality was mostly met.

Similarly, the lack of ability to identify causality is another limitation of this study (Price & Murnan, 2004). Multiple regression is used to identify predictive relationships between independent variables and the dependent variable. Since this was not an experimental design, causation could not be determined. While certain subscales of the independent variables did predict variability in marriage satisfaction, it is not possible to determine if these were the only factors influencing marriage satisfaction. For example, the parenting stress subscales of parent/child dysfunctional interaction and difficult child were found to be significant predictors of marriage satisfaction. The limited scope of the survey design would not have been able to ascertain if other variables, such as family financial constraints, the presence of siblings, or spouse substance abuse also impacted marriage satisfaction (e.g., Maroufizadeh et al., 2019).

Another potential limitation of this study was the participant dropout rate (Price & Murnan, 2004). A total number of 249 individuals responded to this study. After the removal of some respondents due to exclusion criteria and incomplete responses, a final sample size of 206 respondents was included in the final analyses. While it is possible that respondents did not complete the survey due to its length, it is also possible that asking CHD parents to respond honestly about their levels of stress may have led to higher rates of dropout if they became uncomfortable with the survey items. If parents with less parenting stress were more likely to complete the survey, the resulting marriage satisfaction data would not be representative of the population of CHD parents.

Finally, another potential limitation to these results could have been the severity of a child's heart defect. Since CHD is a spectrum diagnosis that varies significantly among individuals in severity, prognosis, treatment, and long-term care, the results garnered may not accurately convey a uniform relationship between CHD severity and parental stress/coping/support, and marriage satisfaction. While specific diagnostic demographic information was collected from participants, information about illness severity and treatment was not. Illness severity may have varied significantly and differentially impacted parental stress, parental support, parental coping, and marriage satisfaction (e.g., Popp et al., 2014).

Recommendations

Recruitment of participants in the study was initially very slow. One explanation for the response rate may have been the length of the survey. With multiple assessments combined to measure the identified factors of parental stress, parental support, parental

coping, and marriage satisfaction, the length of the survey may have been a deterring factor for survey completion. For future research measuring these parenting characteristics, a shorter survey may yield more completed responses.

The sample size recommended based upon a power analysis was achieved for this study. However, there was somewhat of a lack of variability in the gender and education level of participants. This limited the generalizability of the research findings due to a lack of male respondents and respondents with education lower than a college degree. Future research should target more fathers and individuals with lower levels of education, since these were not well-represented in this study. Focus in this area could determine if there are any differences in the findings amongst these additional populations. In particular, further research targeting fathers of children with CHD may also help to identify if stress levels, support, and coping differ significantly from that reported by this study, which included data from 66% mothers.

I found that while the parent/child dysfunctional interaction subscale of parental stress was a significant predictor of marriage satisfaction, the difficult child subscale was not. This seems to infer that the behavior and temperament of a child may not negatively impact marriage satisfaction to the level that having a negative relationship/failure to bond with a child may. Therefore, additional research could focus specifically upon what aspects of parent/child dysfunctional interaction, such as jealousy over a spouse bonding more quickly with a child, may directly impact marriage satisfaction.

Results also indicated that while the difficult child subscale of parental stress was not a significant predictor of total marriage satisfaction, it was a significant predictor of

idealistic distortion. This seems to indicate that raising a child perceived to be behaviorally difficult may lead a parent to have a more realistic view of their relationships, as well as being more open to discussing their problems. Further research including such individuals with high difficult child and low idealistic distortion scores could be beneficial, as their more realistic/open views could make them open/amenable candidates for the feedback and advice that a family or parental counselor could provide.

The parental coping subscale of maintaining social support, self-esteem, and psychological stability was found to be a statistically significant predictor of idealistic distortion. This showed that those participants who placed a lot of effort into developing relationships with others and engaged in activities to enhance feelings of self-worth also tended to present their relationships in a highly favorable manner. Additional research in this area could focus on multiple areas, such as what personality traits or social pressures motivate individuals to portray their relationships in an overly favorable manner. Research could also focus on the relationship between idealistic distortion scores, parental coping scores, and divorce rates. Studies into divorce rates could uncover data pertaining to whether or not a person enhancing feelings of self-worth and presenting their relationships in a highly favorable manner have long-term benefits or drawbacks for marriage stability.

The parental support subscale of spouse/parenting partner relationship was found to significantly predict all levels of marital satisfaction (idealistic distortion, marriage satisfaction, and total marriage satisfaction). This interesting finding seems to indicate that having the emotional and active support of the other parent in the areas of child

management has a positive impact on marriage satisfaction. If the spouse/parenting partner relationship component of parental support is very strong, marriage satisfaction tends to be higher and partners are typically portrayed in a positive light. If the spouse/parenting partner relationship component of parental support is lacking, marriage satisfaction tends to be lower and partners are typically portrayed in a negative light. Further research in the area of the spouse/parenting partner relationship component of parental support could focus on how interventions such as couples counseling and parenting classes could bolster the spouse/parenting partner relationship and, therefore, improve marriage satisfaction. Additionally, follow-up research involving couples, instead of merely one partner, could provide further insight into how the spouse/parenting partner relationship impacts marriage satisfaction.

Lastly, the collection of qualitative data on married couples of children with CHD is also needed in furthering research in this area. While this quantitative study highlighted variables that were significant predictors of marriage satisfaction or dissatisfaction, information collected through interviews with parents or case studies could uncover specific areas in the parenting relationship that suffer when raising a child with these diagnoses. Obtaining data on the lived experiences of these CHD parents could provide insight into the specific medical and relationship challenges that they face, as compared to parents raising a child with a different diagnosis. In this way, medical and psychological care providers could better support these parents and their children.

Implications

The findings from this research provide several possible implications for positive social change at the family, organizational, and societal levels. This research has provided additional foundation to the body of knowledge on marriage satisfaction for parents of children with congenital heart defects. Additionally, it has uncovered several aspects of parental stress, parental support, and parental coping that can impact marriage satisfaction amongst parents raising a child with CHD. Although previous research has examined parental stress and its role in raising a child with a CHD, it has not examined how this parental stress impacted marital satisfaction (Nadeem et al., 2016). Furthermore, research has not addressed the factor of parental coping, and how it could impact marriage satisfaction among parents of children with CHD. Research into this area is significant, as CHD can place parents at a higher risk of psychological dysfunction than parents of children without CHD (Hearps et al., 2014). With increased knowledge in these specific areas, improvements could potentially be made to counseling services, support groups, and parental education resources (Ahn, Lee, & Choi, 2014).

Results from this study identified aspects of parental stress, parental support, and parental coping that impact marriage satisfaction. For example, the finding that marriage satisfaction is significantly impacted by a parent/child's dysfunctional interaction could provide implications for organizational practice moving forward. Programs and organizations that provide therapeutic services to these families/couples could modify parental therapy models to incorporate the parent's perception of their relationship with their child. Since parents that scored highly in parent/child dysfunctional interaction

perceive that the child is a negative element in their life, mindfulness therapy and cognitive-behavioral techniques could attempt to reframe these emotional beliefs.

An increased understanding about the specific benefits of the spouse/parenting partner relationship component of parental support could also be a potential implication of this study. Since the parental support subscale of spouse/parenting partner relationship was a significant predictor across all levels of marriage satisfaction, it appears to play a prominent role in marriage health. With specific regard to the CHD community, parent support groups, charities, and awareness organizations could emphasize the importance of the emotional and active support of spouses when raising a child with CHD. This should include helping partners feel comfortable advocating for their child to healthcare providers, allowing one's significant other to communicate their worries freely, and embedded a parent's alone time, when needed. Since a lack of mutual support for a child is a symptom of a dysfunctional relationship, practitioners and clinicians should encourage the active engagement of both parents in the ongoing care and support of their children with CHD. Adapting a person-centered therapeutic model for parents of children with CHD based upon this information could focus on specific familial relationship issues unique to this population.

From a larger perspective, the results from this study could have practical applications in better understanding the specific impact raising a child with CHD has upon one's marriage. Positive social change could be cultivated by setting up specialized treatment and counseling plans for these couples that focus upon these specific areas. Finding a significant relationship between certain aspects of parental stress, parental

support, and marriage satisfaction, could be used to help these parents garner an increased awareness of potential triggers for stress and marriage dissatisfaction. In addition, the development of further academic, financial, and social supports to augment the struggles of these parents could lead to more family stability. New theoretical models could be developed to adequately identify these sources of parenting stress among the CHD population. Many theoretical perspectives on parenting/child rearing arise from a foundation of healthy children. Raising a child with a complex and life-long medical condition, such as CHD, includes a multitude of unique familial challenges. By tailoring certain parental coping strategies to mitigate the negative effects of stress related to raising a child with CHD, it can be possible to bolster couple communication, cooperation, and satisfaction. If this can be achieved, family dynamics and stability could become more stable for children challenged with CHD.

Conclusion

This study was conducted to address a gap in literature by examining how parental stress, parental support, and coping impact marriage satisfaction amongst parents of children with CHD. Children diagnosed with CHD typically require specialized care, surgical intervention, and a myriad of additional life-long supports. For these parents, caring for their child has led to higher perceived levels of stress compared to the parents of children without CHD. While previous research has uncovered a relationship between parental stress and raising a child with CHD, they have failed to identify the impact that parental stress, support, and coping has on the marriage satisfaction of these parents.

The results of this study identified both the difficult child subscale of parental stress and the coping subscale of maintaining social support, self-esteem, and psychological stability as significant predictors of idealistic distortion. This could suggest that the more difficult that a parent perceives their child to be, the more likely that the parent will have a realistic view of the relationships and will be open to discussing problems. Also, parents who typically place a lot of effort into developing relationships with others also tend to present their relationships in a highly favorable manner. Parent/child dysfunctional interaction as a statistically significant predictor of marital satisfaction and total marriage satisfaction. This could suggest that the more dysfunction that a parent perceives in their interactions with their child, the less satisfaction they have in their marriage. The spouse/parenting partner relationship was found to be a statistically significant predictor of across all measures of the ENRICH Marital Satisfaction Scale. The less emotional and active support of one's partner, the more likely they were to perceive lower levels of marriage satisfaction, while also being less likely to paint their relationship with their partner in a positive light. Measures of parental distress, maintaining family integration, and understanding the healthcare situation were not found to be statistically significant predictors for any of the measures of marriage satisfaction.

This study has made contributions to the understanding on how parental stress, support, and coping can impact marriage satisfaction for parents of children with CHD. It provides insight into the unique sources of parenting stress and marital challenges that parents of children with CHD face. These findings can provide several positive implications for social change at the family, organizational, and societal levels. By

tailoring certain parental coping and support strategies to mitigate the negative effects of stress related to raising a child with CHD, it can be possible to bolster marital communication, cooperation, and satisfaction.

References

Abidin, R. R. (1990a). *Parenting Stress Index (PSI)*. Pediatric Psychology Press.

Abidin, R. R. (1990b). *Parenting stress index-short form*. Pediatric Psychology Press.

Abidin, R. R. (1990c). The stress of parenting. *Journal of Clinical Child Psychology, 19,* 297-400.

Abidin, R. R. (2012). Parenting Stress Index, Fourth Edition: Professional Manual. Psychological Assessment Resources, Inc.

Ahn, J. A., Lee, S., & Choi, J. Y. (2014). Comparison of coping strategy and disease knowledge in dyads of parents and their adolescent with congenital heart disease. *Journal of Cardiovascular Nursing*, *29*(6), 508-516. https://doi.org/10.1097/jcn.0000000000000090

Ailes, E. C., Gilboa, S. M., Honein, M. A., & Oster, M. E. (2015). Estimated number of infants detected and missed by critical congenital heart defect screening. *Pediatrics*, *135*(6), 1000-1008. https://doi.org/10.1542/peds.2014-3662

Anastopoulos, A. D., Guevremont, D. C., Shelton, T. L., & DuPaul, G. J. (1992). Parenting stress among families of children with attention deficit hyperactivity disorder. *Journal of Abnormal Child Psychology*, *20*(5), 503-520. https://doi.org/10.1007/BF00916812

Arya, B., Glickstein, J. S., Levasseur, S. M., & Williams, I. A. (2013). Parents of children with congenital heart disease prefer more information than cardiologists provide. *Congenital Heart Hisease*, *8*(1), 78-85. https://doi.org/10.1111/j.1747-0803.2012.00706.x

Barakat, L. P., Patterson, C. A., Daniel, L. C., & Dampier, C. (2008). Quality of life among adolescents with sickle cell disease: mediation of pain by internalizing symptoms and parenting stress. *Health and Quality of Life Outcomes*, *6*(1), 60.

Barroso, N. E., Hungerford, G. M., Garcia, D., Graziano, P. A., & Bagner, D. M. (2016). Psychometric properties of the Parenting Stress Index-Short Form (PSI-SF) in a high-risk sample of mothers and their infants. *Psychological Assessment*, *28*(10), 1331. https://doi.org/10.1037/pas0000257

Bazzano, A., Wolfe, C., Zylowska, L., Wang, S., Schuster, E., Barrett, C., & Lehrer, D. (2015). Mindfulness based stress reduction (MBSR) for parents and caregivers of individuals with developmental disabilities: a community-based approach. *Journal of Child and Family Studies*, *24*(2), 298-308.

Berant, E., Mikulincer, M., & Florian, V. (2003). Marital satisfaction among mothers of infants with congenital heart disease: The contribution of illness severity, attachment style, and the coping process. *Anxiety, Stress, and Coping*, *16*(4), 397-415. https://doi.org/10.1080/10615580031000090079

Best, K. E., & Rankin, J. (2016). Long-term survival of individuals born with congenital heart disease: a systematic review and meta-analysis. *Journal of the American Heart Association*, *5*(6), e002846. https://doi.org/10.1161/JAHA.115.002846

Bögels, S. M., Hellemans, J., van Deursen, S., Römer, M., & van der Meulen, R. (2014). Mindful parenting in mental health care: Effects on parental and child psychopathology, parental stress, parenting, coparenting, and marital functioning. *Mindfulness*, *5*(5), 536-551. 10.1007/s12671-013-0209-7

Bowen, M. (1976). Theory in the practice of psychotherapy. In P. J. Guerin, Jr. (Ed.), Family therapy: Theory and practice (pp. 42-90). Garner Press.

Bratt, E. L., Järvholm, S., Ekman-Joelsson, B. M., Mattson, L. Å., & Mellander, M. (2015). Parent's experiences of counselling and their need for support following a prenatal diagnosis of congenital heart disease-a qualitative study in a Swedish context. *BMC Pregnancy and Childbirth*, *15*(1), 171. DOI 10.1186/s12884-015-0610-4

Brenner, M., Cote, S. M., Boivin, M., & Tremblay, R. E. (2016). Severe congenital malformations, family functioning and parents' separation/divorce: A longitudinal study. *Child: Care, Health and Development*, *42*(1), 16-24. https://doi.org/10.1111/cch.12269

Bruce, E.; Lilja, C.; & Sundin, K. (2014). Mothers' lived experiences of support when living with young children with Congenital Heart Defects. *Journal for Specialists in Pediatric Nursing, 19(1),* 54-67. https://doi.org/10.1111/jspn.12049

Burke, K., Muscara, F., McCarthy, M., Dimovski, A., Hearps, S., Anderson, V., & Walser, R. (2014). Adapting acceptance and commitment therapy for parents of children with life-threatening illness: Pilot study. *Families, Systems, & Health*, *32*(1), p 122. https://doi.org/10.1037/fsh0000012

Camfield, C., Breau, L., & Camfield, P. (2001). Impact of pediatric epilepsy on the family: A new scale for clinical and research use. Epilepsia, 42, 104–112. https://doi.org/10.1046/j.1528-1157.2001.081420.x

Celano, M., Klinnert, M. D., Holsey, C. N., & McQuaid, E. L. (2011). Validity of the

family asthma management system scale with an urban African-American sample. *Journal of Pediatric Psychology, 36*, 576–585. https://doi.org/10.1093/jpepsy/jsp083

Centers for Disease Control and Prevention. (2016, August 01) Data & Statistics. Retrieved from: https://www.cdc.gov/ncbddd/heartdefects/data.html

Chiou, H. H., & Hsieh, L. P. (2008). Comparative study of children's self-concepts and parenting stress between families of children with epilepsy and asthma. *Journal of Nursing Research*, *16*(1), 65-74. doi: 10.1097/01.JNR.0000387291.61183.41

Cohen, J. (1969). *Statistical power analysis for the behavioral sciences.* San Diego, CA: Academic Press.

Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of pediatric psychology*, *38*(8), 809-828. https://doi.org/10.1093/jpepsy/jst049

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, CA: Sage.

Cridland, E. K., Jones, S. C., Magee, C. A., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. Autism, 18(3), 213-222. https://doi.org/10.1177/1362361312472261

Crnic, K., & Ross, E. (2017). Parenting stress and parental efficacy. In *Parental Stress and Early Child Development* (pp. 263-284). Springer International Publishing. https://doi.org/10.1007/978-3-319-55376-4_11

Dale, M. T., Solberg, Ø., Holmstrøm, H., Landolt, M. A., Eskedal, L. T., & Vollrath, M.

E. (2013). Relationship satisfaction among mothers of children with congenital heart defects: A prospective case-cohort study. *Journal of pediatric psychology*, *38*(8), 915-926. https://doi.org/10.1093/jpepsy/jst038

Darling, C.; Senatore, N., & Strachan, J. (2012). Fathers of Children with Disabilities: Stress and Life Satisfaction. *Stress & Health: Journal of the International Society for the Investigation of Stress, 28 (4),* 269-278. DOI: 10.1002/smi.1427.

DeMaso, D. R., Calderon, J., Taylor, G. A., Holland, J. E., Stopp, C., White, M. T., ... & Newburger, J. W. (2017). Psychiatric disorders in adolescents with single ventricle congenital heart disease. *Pediatrics*, e20162241.

DeMore, M., Adams, C., Wilson, N., & Hogan, M. B. (2005). Parenting stress, difficult child behavior, and use of routines in relation to adherence in pediatric asthma. Children's Health Care, 34, 245–259. https://doi.org/10.1207/s15326888chc3404_1

Deng, L. X., Khan, A. M., Drajpuch, D., Fuller, S., Ludmir, J., Mascio, C. E., ... & Kim, Y. Y. (2016). Prevalence and correlates of post-traumatic stress disorder in adults with congenital heart disease. *The American journal of cardiology*, *117*(5), 853-857. https://doi.org/10.1016/j.amjcard.2015.11.065

Doherty, N.; McCusker, C.; Molloy, B.; Mulholland, C.; Rooney, N.; Craig, B.; Sands, A.; Stewart, M.; & Casey, F. (2009). Predictors of psychological functioning in mothers and fathers of infants born with severe congenital heart disease. *Journal*

of Reproductive and Infant Psychology, 27(4), 390-400. https://doi.org/10.1080/02646830903190920

Fagnano, M., van Wijngaarden, E., Connolly, H. V., Carno, M. A., Forbes-Jones, E., & Halterman, J. S. (2009). Sleep-disordered breathing and behaviors of inner-city children with asthma. Pediatrics, 124, 218–225. https://doi.org/10.1542/peds.2008-2525

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analysis. *Behavior Research Methods*, 41, 1149-1160. 10.3758/BRM.41.4.1149

Feizi, A., Najmi, B., Salesi, A., Chorami, M., & Hoveidafar, R. (2014). Parenting stress among mothers of children with different physical, mental, and psychological problems. *Journal of research in medical sciences: the official journal of Isfahan University of Medical Sciences*, *19*(2), 145.s

Feldman, M.; McDonald, L.; Serbin, L.; Stack, D.; Secco, L.; & Yu, T. (2007). Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. *Journal of Intellectual Disability Research, 51(8),* 606-619. DOI: 10.1111/j.1365-2788.2006.00941.x

Fournier, D. G., Olson, D. H. & Druckman, J. M. (1983). Assessing marital and premarital relationships: The PREPARE-ENRICH Inventories. In E. E. Filsinger (Ed.), Marriage and family assessment (pp. 229-250). Beverly Hills, CA: Sage Publishing.

Fowers, B. J. (1988). Demographics are not dead: A reexamination of couple

demographics and marital satisfaction. Unpublished manuscript, University of New Mexico, Department of Counseling and Family Studies, Albuquerque, NM.

Fowers. B. J. (1990). An interactional approach to standardized marital assessment: A literature review. Family Relations. 39, 368-377. https://doi.org/10.2307/585215

Fowers, B. J., Applegate, B., Olson, D. H., & Pomerantz, B. (1992a, August). Reexamining marital conventionalization: A measure of marital quality, hypersatisfaction, or denial? Poster presented at the 100th Annual Convention of the American Psychological Association, Washington, D.C.

Fowers, B. J., Applegate, B., Olson, D. H., & Pomerantz, B. (1992b, November). Social desirability or hypersatisfaction? Examining the factor structure of marital satisfaction and conventionalization for husbands and wives. Poster presented at the 54th Annual Conference of the National council on Family Relations, Orlando, FL.

Fowers, B. J., & Olson, D. H. (1989). ENRICH marital inventory: A discriminant validity and cross-validation assessment. Journal of Marital and Family Therapy, 15, 65-79. https://doi.org/10.1111/j.1752-0606.1989.tb00777.x

Fowers, B. J., & Olson, D. H. (1993). ENRICH Marital Satisfaction Scale: A brief research and clinical tool. *Journal of Family psychology*, *7*(2), 176. https://doi.org/10.1037/0893-3200.7.2.176

Frankfort-Nachmias, C., & Nachmias, D. (2012). Research methods in the social sciences (8th ed.). New York: Worth.

Funk, J. L., & Rogge, R. D. (2007). Testing the ruler with item response theory:

increasing precision of measurement for relationship satisfaction with the Couples Satisfaction Index. *Journal of Family Psychology*, *21*(4), 572. https://doi.org/10.1037/0893-3200.21.4.572

Gabriel, B., Bodenmann, G., & Beach, S. R. (2016). Gender Differences in Observed and Perceived Stress and Coping in Couples with a Depressed Partner. *Open Journal of Depression*, *5*(02), 7. 10.4236/ojd.2016.52002

Gardner J. (2007). What you need to know about cystic fibrosis. *Nursing, 37(7),* 52-55. doi: 10.1097/01.NURSE.0000279437.30155.1e

Gilboa, S. M., Devine, O. J., Kucik, J. E., Oster, M. E., Riehle-Colarusso, T., Nembhard, W. N., ... & Marelli, A. J. (2016). Congenital heart defects in the United States. *Circulation*, *134*(2), 101-109. https://doi.org/10.1161/CIRCULATIONAHA.115.019307

Goldbeck, L. (2001). Parental coping with the diagnosis of childhood cancer: gender effects, dissimilarity within couples, and quality of life. *Psycho- Oncology, 10*(4), 325-335. https://doi.org/10.1002/pon.530

Goldberg, S., Morris, P., Simmons, R. J., Fowler, R. S., & Levison, H. (1990). Chronic illness in infancy and parenting stress: A comparison of three groups of parents. Journal of Pediatric Psychology, 15, 347–358. https://doi.org/10.1093/jpepsy/15.3.347

Golfenshtein, N., Srulovici, E., & Deatrick, J. A. (2016). Interventions for reducing

parenting stress in families with pediatric conditions: An integrative review. *Journal of family nursing*, *22*(4), 460-492. https://doi.org/10.1177/1074840716676083

Golfenshtein, N., Hanlon, A. L., Deatrick, J. A., & Medoff-Cooper, B. (2017). Parenting Stress in Parents of Infants With Congenital Heart Disease and Parents of Healthy Infants: The First Year of Life. *Comprehensive child and adolescent nursing*, *40*(4), 294-314. https://doi.org/10.1080/24694193.2017.1372532

Gothwal, V. K., Bharani, S., & Reddy, S. P. (2015). Measuring coping in parents of children with disabilities: a rasch model approach. *PloS one*, *10*(3), e0118189.

Gupta, V. (2007). Comparison of Parenting Stress in Different Developmental Disabilities. *Journal of Developmental & Physical Disabilities. 19 (4),* 417-425. DOI: 10.1007/s10882-007-9060-x.

Harper, F.W., Peterson, A.M., Uphold, H., Albrecht, T.L., Taub, J.W., Orom, H., … & Penner, L.A. (2013.) Longitudinal study of parent caregiving self-efficacy and parent stress reactions with pediatric cancer treatment procedures. *Psycho-Oncology, 22*(7), 1658-1664. https://doi.org/10.1002/pon.3199

Haskett, M., Scott, S., Willoughby, L., & Nears, K. (2006). The Parent Opinion Questionnaire and Child Vignettes for use with abusive parents: Assessment of psychometric properties. Journal of Family Violence, 21, 137-151. DOI: 10.1007/s10896-005-9010-2

Haskett, M. E., Ahern, L. S., Ward, C. S., & Allaire, J. C. (2006). Factor structure and

validity of the parenting stress index-short form. *Journal of Clinical Child & Adolescent Psychology*, *35*(2), 302-312. https://doi.org/10.1207/s15374424jccp3502_14

Hatton, C.; Emerson, E.; Graham, H.; Blacher, J., & Llewellyn, G. (2010). Changes in Family Composition and Marital Status in Families with a Young Child with Cognitive Delay. *Journal of Applied Research in Intellectual Disabilities, 23 (1),* 14-26. DOI: 10.1111/j.1468-3148.2009.00543.x.

Hearps, S. J., McCarthy, M. C., Muscara, F., Hearps, S. J., Burke, K., Jones, B., & Anderson, V. (2014). Psychosocial risk in families of infants undergoing surgery for a serious congenital heart disease. *Cardiology in the Young*, *24*(04), 632-639. doi:10.1017/S1047951113000760

Helgeson, V. S., Becker, D., Escobar, O., & Siminerio, L. (2012). Families with children with diabetes: Implications of parenting stress for parent and childhealth. Journal of Pediatric Psychology, 37, 467–478. https://doi.org/10.1093/jpepsy/jsr110

Hilliard, M. E., Monaghan, M., Cogen, F. R., & Streisand, R. (2011). Parent stress and child behaviour among young children with type 1 diabetes. *Child: care, health and development*, *37*(2), 224-232. https://doi.org/10.1111/j.1365-2214.2010.01162.x

Hullmann, S. E., Wolfe-Christensen, C., Ryan, J. L., Fedele, D. A., Rambo, P. L., Chaney, J. M., & Mullins, L. L. (2010). Parental overprotection, perceived child vulnerability, and parenting stress: a cross-illness comparison. *Journal of*

clinical psychology in medical settings, *17*(4), 357-365. DOI: 10.1007/s10880-010-9213-4

Kaplan, S. G., Arnold, E. M., Irby, M. B., Boles, K. A., & Skelton, J. A. (2014). Family systems theory and obesity treatment: applications for clinicians. *ICAN: Infant, Child, & Adolescent Nutrition*, *6*(1), 24-29. https://doi.org/10.1177/1941406413516001

Kazak, A. E., Boeving, C. A., Alderfer, M. A., Hwang, W. T., & Reilly, A. (2005). Posttraumatic stress symptoms during treatment in parents of children with cancer. *Journal of Clinical Oncology*, *23*(30), 7405-7410. DOI: 10.1200/jco.2005.09.110

Kennedy, S. C., & Gordon, K. (2017). Effects of integrated play therapy on relationship satisfaction and intimacy within couples counseling: A clinical case study. *The Family Journal*, *25*(4), 313–321. https://doiorg.ezp.waldenulibrary.org/10.1177/1066480717732169

Lakkis, N. A., Khoury, J. M., Mahmassani, D. M., Ramia, M. S., & Hamadeh, G. N. (2016). Psychological distress and coping strategies in parents of children with cancer in Lebanon. Psycho-Oncology, 25(4), 428-434. https://doi.org/10.1002/pon.3934

Lawoko, S. (2007). Factors influencing satisfaction and well-being among parents of congenital heart disease children: Development of a conceptual model based on the literature review. *Scandinavian Journal of Caring Sciences, 21(1),* 106-117. https://doi.org/10.1111/j.1471-6712.2007.00444.x

Lazarus, R.S. (1966). *Psychological Stress and the Coping Process.* New York: McGraw-Hill.

Lazarus, R.S. & Cohen, J.B. (1977). "Environmental Stress". In I. Altman and J.F. Wohlwill (eds.), *Human Behavior and Environment.* (Vol 2) New York: Plenum

Lazarus, R. S., & Folkman, S. (1984). *Stress, coping and appraisal.* New York: Springer Publishing Company.

Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *Journal of personality and social psychology*, *50*(5), 992. DOI: 10.1037//0022-3514.50.5.992

Folkman, S., & Lazarus, R. S. (1988). Coping as a mediator of emotion. *Journal of personality and social psychology*, *54*(3), 466.

Lee, S. & Kim, S. (2012). The life experiences of Korean children and adolescents with complex congenital heart disease: A qualitative study. *Nursing & Health Sciences, 14(3),* 398-404. DOI: 10.1111/j.1442-2018.2012.00709.x.

Lee, S. J., Gopalan, G., & Harrington, D. (2016). Validation of the Parenting Stress Index–Short Form With Minority Caregivers. *Research on social work practice*, *26*(4), 429-440. https://doi.org/10.1177/1049731514554854

Lee, M. H., Park, C., Matthews, A. K., & Hsieh, K. (2017). Differences in physical health, and health behaviors between family caregivers of children with and without disabilities. *Disability and health journal*, *10*(4), 565-570. https://doi.org/10.1016/j.dhjo.2017.03.007

Leon, A., Wallenberg, J., & Holliker, S. (2013). The impact of child congenital heart disease on parents of very young children: Considerations for social work practice. *Families in Society: The Journal of Contemporary Social Services*, *94*(2), 129-135. https://doi.org/10.1606/1044-3894.4285

Lisanti, A. J., Allen, L. R., Kelly, L., & Medoff-Cooper, B. (2017). Maternal Stress and Anxiety in the Pediatric Cardiac Intensive Care Unit. *American Journal of Critical Care*, *26*(2), 118-125. https://doi.org/10.4037/ajcc2017266

Litzelman, K., Catrine, K., Gangnon, R., & Witt, W. P. (2011). Quality of life among parents of children with cancer or brain tumors: The impact of child characteristics and parental psychosocial factors. Quality of Life Research, 20, 1261–1269. DOI: 10.1007/s11136-011-9854-2

Logan, D. E., Radcliffe, J., & Smith-Whitley, K. (2002). Parent factors and adolescent sickle cell disease: Associations with patterns of health service use. Journal of Pediatric Psychology, 27, 475–484. https://doi.org/10.1093/jpepsy/27.5.475

López, R., Frangini, P., Ramírez, M., Valenzuela, P. M., Terrazas, C., Pérez, C. A., ... & Trachsel, M. (2016). Well-Being and Agency in Parents of Children With Congenital Heart Disease A Survey in Chile. *World Journal for Pediatric and Congenital Heart Surgery*, *7*(2), 139-145. https://doi.org/10.1177/2150135115623284

Malm-Buatsi, E., Aston, C. E., Ryan, J., Tao, Y., Palmer, B. W., Kropp, B. P., ... &

Frimberger, D. (2015). Mental health and parenting characteristics of caregivers of children with spina bifida. *Journal of Pediatric Urology*, *11*(2), 65-68. https://doi.org/10.1016/j.jpurol.2014.09.009

Marelli, A. J., Mackie, A. S., Ionescu-Ittu, R., Rahme, E., & Pilote, L. (2007). Congenital heart disease in the general population. *Circulation*, *115*(2), 163-172. DOI: 10.1161/circulationaha.106.627224

Maroufizadeh, S., Hosseini, M., Foroushani, A. R., Omani-Samani, R., & Amini, P. (2019). The Relationship between Perceived Stress and Marital Satisfaction in Couples with Infertility: Actor-Partner Interdependence Model. *Int J Fertil Steril*, *13*(1). doi: 10.22074/ijfs.2019.5437

Marshall, M. N. (1996). Sampling for qualitative research. *Family practice*, *13*(6), 522-526. https://doi.org/10.1093/fampra/13.6.522

Mazer, P., Gischler, S. J., Koot, H. M., Tibboel, D., van Dijk, M., & Duivenvoorden, H. J. (2008). Impact of a child with congenital anomalies on parents (ICCAP) questionnaire; a psychometric analysis. *Health and Quality of Life Outcomes*, *6*(1), 102. doi:10.1186/1477-7525-6-102

McCubbin, H.I., McCubbin, M.A., Patterson, J.M., Cauble, A.E., Wilson, L.R. & Warwick, W. (1983). CHIP-Coping Health Inventory for Parents: An Assessment of Parental Coping Patterns in the Care of the Chronically Ill Child. *Journal of Marriage and the Family*, 359-370. https://doi.org/10.2307/351514

Miller, A. C., Gordon, R. M., Daniele, R. J., & Diller, L. (1992). Stress, appraisal, and

coping in mothers of disabled and nondisabled children. *Journal of Pediatric Psychology*, *17*(5), 587-605. https://doi.org/10.1093/jpepsy/17.5.587

Miller, V.; Luce, M.; & Nelson, R. (2011). Relationship of external influence to parental distress in decision making regarding children with a life-threatening illness. *Journal of Pediatric Psychology, 36(10),* 1102-1112. DOI:10.1093/jpepsy/jsr033

Miodrag, N., Burke, M., Tanner-Smith, E., & Hodapp, R.M. (2015). Adverse health in parents of children with disabilities and chronic health conditions: A meta-analysis using the Parenting Stress Index's Health Sub-domain. *Journal of Intellectual Disability Research, 59*(3), 257-271. https://doi.org/10.1111/jir.12135

Minuchin, S. *(*1974). *Families and family therapy. Cambridge, MA: Harvard University Press.*

Mitrani, V. B., Lewis, J. E., Feaster, D. J., Czaja, S. J., Eisdorfer, C., Schulz, R., & Szapocznik, J. (2006). The role of family functioning in the stress process of dementia caregivers: a structural family framework. *The Gerontologist*, *46*(1), 97-105. https://doi.org/10.1093/geront/46.1.97

Mörelius, E., & Hemmingsson, H. (2014). Parents of children with physical disabilities–perceived health in parents related to the child's sleep problems and need for attention at night. *Child: care, health and development*, *40*(3), 412-418. https://doi.org/10.1111/cch.12079

Nadeem, M., Choudhary, F. R., Parveen, A., & Javaid, F. (2016). Parental Stress among Parents of Children with and without Disabilities. *Pakistan Journal of Social Sciences (PJSS)*, *36*(2).

Olson, D. H., Fournier, D. G. & Druckman, J. M. (1987). Counselor's manual for PREPARE/ENRICH. (Revised edition). Minneapolis, MN, PREPARE/ENRICH, Inc.

Pandya, S. P. (2019). Marital satisfaction of highly qualified professionally achieving women post-retirement: the urban Indian scenario. *Journal of Family Studies*, *25*(1), 61-78. https://doi.org/10.1080/13229400.2016.1194307

Pardeck, J. T. (1989). The Minuchin family stress model: A guide for assessing and treating the impact of marital disruption on children and families. *International Journal of Adolescence and Youth*, *1*(4), 367-377. https://doi.org/10.1080/02673843.1989.9747650

Penfield, W., & Jasper, H. (1954). Epilepsy and the functional anatomy of the human brain.

Pipp-Siegel, S., Sedey, A. L., & Yoshinaga-Itano, C. (2002). Predictors of parental stress in mothers of young children with hearing loss. *Journal of deaf studies and deaf education*, *7*(1), 1-17. https://doi.org/10.1093/deafed/7.1.1

Pinquart, M. (2018). Parenting stress in caregivers of children with chronic physical condition—A meta□analysis. *Stress and Health*, *34*(2), 197-207. https://doi.org/10.1002/smi.2780

Popp, 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: Nursing Care of Children and Families*, *29*(1), 58-64. https://doi.org/10.1016/j.pedn.2013.07.004

Postkammer, P. & Nickolai, S. (1985). Counseling services for the siblings of the handicapped. Elementary School Guidance and Counseling, 20(2), 115-120.

Price, J. H., & Murnan, J. (2004). Research limitations and the necessity of reporting them. *American Journal of Health Education*, *35*(2), 66.

Randall, A. K., & Bodenmann, G. (2017). Stress and its associations with relationship satisfaction. *Current Opinion in Psychology*, *13*, 96-106. http://doi.org/10.1016/j.copsyc.2016.05.010

Rees, D. C., Williams, T. N., & Gladwin, M. T. (2010). Sickle-cell disease. *The Lancet*, *376*(9757), 2018-2031. https://doi.org/10.1016/S0140-6736(10)61029-X

Rempel, G.; Ravindran, V.; Rogers, L.; & Magill-Evans, J. (2013). Parenting under pressure: A grounded theory of parenting young children with life-threatening congenital heart disease. *Journal of Advanced Nursing, 69(3),* 619-630. https://doi.org/10.1111/j.1365-2648.2012.06044.x

Robinson, M., & Neece, C. L. (2015). Marital satisfaction, parental stress, and child behavior problems among parents of young children with developmental delays. *Journal of Mental Health Research in Intellectual Disabilities*, *8*(1), 23-46. https://doi.org/10.1080/19315864.2014.994247

Rodenburg, R., Meijer, A. M., Dekovi, M., & Aldenkamp, A. P. (2007a). Parents of children with enduring epilepsy: predictors of parenting stress and parenting. Epilepsy & Behavior, 11, 197–207. https://doi.org/10.1016/j.yebeh.2007.05.001

Rychik, J., Donaghue, D. D., Levy, S., Fajardo, C., Combs, J., Zhang, X., ... & Diamond,

G. S. (2013). Maternal psychological stress after prenatal diagnosis of congenital heart disease. *The Journal of pediatrics*, *162*(2), 302-307. https://doi.org/10.1016/j.jpeds.2012.07.023

Sarajuuri, A.; Lönnqvist, T.; Schmitt, F.; Almqvist, F.; Jokinen, E. (2012). Patients with univentricular heart in early childhood: Parenting stress and child behaviour. Acta Paediatrica, 101(3), 252-257. DOI:10.1111/j.1651-2227.2011.02509.x.

Schaeffer, N. C., Seltzer, J. A., & Klawitter, M. (1991). Estimating nonresponse and response bias: Resident and nonresident parents' reports about child support. Sociological Methods & Research, 20(1), 30-59. https://doi.org/10.1177/0049124191020001002

Shatla, R., El said Sayyah, H., Azzam, H., & Elsayed, R. M. (2011). Correlates of parental stress and psychopathology in pediatric epilepsy. Annals of Indian Academy of Neurology, 14, 252–256. doi: 10.4103/0972-2327.91938

Sira, N., Desai, P. P., Sullivan, K. J., & Hannon, D. W. (2014). Coping Strategies in Mothers of Children with Heart Defects: A Closer Look Into Spirituality and Internet Utilization. *Journal of Social Service Research*, *40*(5), 606-622. https://doi.org/10.1080/01488376.2014.908808

Silva, L. M., & Schalock, M. (2012). Autism parenting stress index: Initial psychometric evidence. *Journal of Autism and Developmental Disorders*, *42*(4), 566-574. DOI: 10.1007/s10803-011-1274-1

Smith, K., Reinman, L., Schatz, J., & Roberts, C. W. (2018). Parent Perspectives on Pain

Management in Preschool-Age Children With Sickle Cell Disease. *Journal of Pediatric Oncology Nursing*, *35*(1), 16-24. https://doi.org/10.1177/1043454217735829

Snyder, D. K. (1979). Multidimensional assessment of marital satisfaction. *Journal of Marriage and the Family*, 813-823. https://doi.org/10.2307/351481

Solberg, Ø.; Grønning, M.; Holmstrøm, H.; Eskedal, L.; Landolt, M.; & Vollrath, M. (2011). Long-term symptoms of depression and anxiety in mothers of infants with Congenital Heart Defects. *Journal of Pediatric Psychology, 36(2),* 179-187. DOI:10.1093/jpepsy/jsq054.

Solberg, Ø.; Grønning, M.; Holmstrøm, H.; Eskedal, L.; Landolt, M.; & Vollrath, M. (2011). Emotional reactivity in infants with Congenital Heart Defects and maternal symptoms of postnatal depression. *Archives of Women's Mental Health, 14(6),* 487-492. DOI 10.1007/s00737-011-0243-1.

Solberg, Ø.; Grønning, M.; Holmstrøm, H.; Eskedal, L.; Landolt, M.; & Vollrath, M. (2012). Trajectories of maternal mental health: A prospective study of mothers of infants with Congenital Heart Defects from pregnancy to 36 months postpartum. *Journal of Pediatric Psychology, 37(6),* 687-696. DOI:10.1093/jpepsy/jss044

Solomon, C. R., & Breton, J. J. (1999). Early warning signals in relationships between parents and young children with cystic fibrosis. Children's Health Care, 28, 221–240. https://doi.org/10.1207/s15326888chc2803_2

Soulvie, A.; Desai, P., White, C., & Sullivan, B. (2012). Psychological distress

experienced by parents of young children with Congenital Heart Defects: A comprehensive review of literature. *Journal of Social Service Research, 38(4),* 484-502. https://doi.org/10.1080/01488376.2012.696410

Stangor, C. (2011). Reliability and Validity. *Research Methods for the Behavioral Sciences* (4th ed. pp. 88-105). Belmont, CA: Wadsworth.

Sterken, C., Lemiere, J., Van den Berghe, G., & Mesotten, D. (2016). Neurocognitive development after pediatric heart surgery. *Pediatrics*, e20154675.

Streisand, R., Swift, E., Wickmark, T., Chen, R., & Holmes, C. S. (2005). Pediatric parenting stress among parents of children with type 1 diabetes: the role of self-efficacy, responsibility, and fear. *Journal of pediatric psychology*, *30*(6), 513-521. https://doi.org/10.1093/jpepsy/jsi076

Sulkers, E., Tissing, W. J., Brinksma, A., Roodbol, P. F., Kamps, W. A., Stewart, R. E., ... & Fleer, J. (2015). Providing care to a child with cancer: a longitudinal study on the course, predictors, and impact of caregiving stress during the first year after diagnosis. *Psycho-Oncology*, *24*(3), 318-324. https://doi.org/10.1002/pon.3652

Thompson, R. J., Gustafson, K. E., Hamlett, K. W., & Spock, A. (1992). Stress, coping, and family functioning in the psychological adjustment of mothers of children and adolescents with cystic fibrosis. *Journal of Pediatric Psychology*, *17*(5), 573-585. https://doi.org/10.1093/jpepsy/17.5.573

Uskun, E. & Gundogar, D. (2010). The levels of stress, depression and anxiety of parents

of disabled children in Turkey. *Disability & Rehabilitation, 32 (23),* 1917-1927. DOI: 10.3109/09638281003763804.

Uzark, K., & Jones, K. (2003). Parenting stress and children with heart disease. *Journal of Pediatric Health Care, 17*, 163-168. DOI:10.1067/mph.2003.22.

Valicenti-McDermott, M., Lawson, K., Hottinger, K., Seijo, R., Schechtman, M., Shulman, L., & Shinnar, S. (2015). Parental stress in families of children with autism and other developmental disabilities. *Journal of child neurology*, *30*(13), 1728-1735. https://doi.org/10.1177/0883073815579705

Van Brummen, H. J., Bruinse, H. W., Van de Pol, G., Heintz, A. P. M., & Van der Vaart, C. H. (2006). Which factors determine the sexual function 1 year after childbirth?. *BJOG: An International Journal of Obstetrics & Gynaecology*, *113*(8), 914-918. https://doi.org/10.1111/j.1471-0528.2006.01017.x

Varghese, M. (2015). A study on parental stress in the neonatal ICU using parental stressor. *Pediatrics*, *135*(Supplement 1), S9-S9. DOI: https://doi.org/10.1542/peds.2014-3330O

Van der Linde, D., Konings, E. E., Slager, M. A., Witsenburg, M., Helbing, W. A., Takkenberg, J. J., & Roos-Hesselink, J. W. (2011). Birth prevalence of congenital heart disease worldwide. *Journal of the American College of Cardiology*, *58*(21), 2241-2247. doi:10.1016/j.jacc.2011.08.025

Vetere, A. (2001). Structural Family Therapy. *Child Psychology and Psychiatry Review, 6*(3), 133-139. doi:10.1017/s1360641701002672

Vrijmoet-Wiersma C.; Ottenkamp J.; Roozendaal M.; Grootenhuis M.; & Koopman H.

(2009). A multicentric study of disease-related stress, and perceived vulnerability, in parents of children with congenital cardiac disease. *Cardiology in the Young, 19(6),* 608-614. DOI: 10.1017/S1047951109991831

Vrijmoet-Wiersma, C. M. J., Hoekstra-Weebers, J. E. H. M., Margreet de Peinder, W. M. G., Koopman, H. M., Tissing, W. J. E., Treffers, P. D. A., . . . Egeler, R. M. (2010). Psychometric qualities of the Dutch version of the Pediatric Inventory for Parents (PIP): A multi-center study. Psycho-Oncology, 19, 368–375. https://doi.org/10.1002/pon.1571

Ward, C., Massie, J., Glazner, J., Sheehan, J., Canterford, L., Armstrong, D., ... & Hiscock, H. (2009). Problem behaviours and parenting in preschool children with cystic fibrosis. *Archives of disease in childhood*. http://dx.doi.org/10.1136/adc.2008.150789

Weinberg, M., Besser, A., Zeigler-Hill, V., & Neria, Y. (2018). Marital satisfaction and trauma-related symptoms among injured survivors of terror attacks and their spouses. *Journal of Social and Personal Relationships*, *35*(3), 395-407. https://doi.org/10.1177/0265407517691367

Weitlauf, A. S., Vehorn, A. C., Taylor, J. L., & Warren, Z. E. (2014). Relationship satisfaction, parenting stress, and depression in mothers of children with autism. *Autism*, *18*(2), 194-198. https://doi.org/10.1177/1362361312458039

Werner, H., Latal, B., Valsangiacomo Buechel, E., Beck, I., & Landolt, M. A. (2014).

The impact of an infant's severe congenital heart disease on the family: a prospective cohort study. *Congenital heart disease*, *9*(3), 203-210. https://doi.org/10.1111/chd.12123

Whiting, M. (2014). What it means to be the parent of a child with a disability or complex health need. Nursing *Children* & Young People, 26 (5), 26-29. DOI: 10.7748/ncyp.26.5.26.e390

Wirrell, E. C., Wood, L., Hamiwka, L. D., & Sherman, E. M. (2008). Parenting stress in mothers of children with intractable epilepsy. *Epilepsy & Behavior*, *13*(1), 169-173.

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*, 264-276. https://doi.org/10.1016/j.ridd.2014.10.011

Wren, C., Richmond, S., & Donaldson, L. (1999). Presentation of congenital heart disease in infancy: implications for routine examination. *Archives of Disease in Childhood-Fetal and Neonatal Edition*, *80*(1), F49-F53.

Wu, Y. P., Graves, M. M., Roberts, M. C., & Mitchell, A. C. (2010). Is insulin pump therapy better than injection for adolescents with diabetes? Diabetes Research And Clinical Practice, 89, 121–125. https://doi.org/10.1016/j.diabres.2010.04.010

Zanon, R. B., Da Silva, M. A., De Mendonça Filho, E. J., Bandeira, D. R., Dos Santos,

M. A., Halpern, R., & Bosa, C. A. (2017). Brazilian study of adaptation and psychometric properties of the Coping Health Inventory for Parents. *Psicologia: Reflexão e Crítica*, *30*(1), 10. https://doi.org/10.1186/s41155-017-0065-9

Appendix A: Demographic Questionnaire

Please provide the following demographic information regarding you and your child before proceeding to the survey questions. Mark your answer by making the appropriate selection from the drop down menu.

1. Age of Parent:
2. Gender of Parent:
    - Male
    - Female
3. Are you the biological parent of the child diagnosed with CHD?
    - Yes
    - No
4. Do you currently have custody and /or guardianship of your child?
    - Yes
    - No
5. Primary Language:
    - English
    - Other
6. Highest Level of Education:
    - Did not complete High School
    - High School Diploma
    - College Degree
    - Graduate Degree
7. Ethnicity of Parent:
    - American Indian or Alaska Native
    - Asian

- Black or African American
- Hispanic or Latino
- Mixed Ethnicity
- Native Hawaiian or Pacific Islander
- White or Caucasian
- Other

8. Average Annual Income:
    - $30,000 or less
    - $31,000-$50,000
    - $51,000-$70,000
    - $71,000-$90,000
    - $91,000 or more
9. Are you currently marriage and living with your spouse?
    - Yes
    - No
10. How long have you been married to your spouse?
    - 1-5 years
    - 6-10 years
    - 11 years or longer
11. Child Primary Diagnosis:
    - Tetralogy of Fallot
    - Transposition of the great arteries
    - Hypoplastic left/right heart syndrome

- ASD/VSD
- Other

12. Age of Child:

13. Child's age at initial diagnosis:

14. Total number of children in the home:

Appendix B: License Agreement for use of PSI-4

LICENSE AGREEMENT

THIS AGREEMENT, made this June 28, 2019, by and between Psychological Assessment Resources, Inc., a Florida Corporation, with its principal offices, hereinafter referred to as PAR, and David Kropff, hereinafter referred to as Licensee.

1) RECITALS

PAR has developed and holds all copyrights and distribution rights to certain psychological tests and related materials as listed in Schedule A, hereinafter called "Test". The Test consists of PAR's items, scoring keys, scales, profiles, standard-score conversion tables, norms tables, interpretive information, and related materials created, prepared, devised, and combined by PAR for the administration, scoring, reporting, and analysis of the Test, and includes the words, symbols, numbers, and letters used to represent the Test. Licensee desires to develop automated procedures for the secure and encrypted administration of the Test through Licensee's secure internet assessment website utilizing Qualtrics. The access to Licensee's website will be by invitation only in connection with Licensee's research titled, *Stress, Coping, Social Support, and Marriage Satisfaction in Parents of Children with Congenital Heart Defects* and to subjects for this research purpose only (the "Limited Purpose(s)"). Unless permitted to do so by a separate license agreement, Licensee only has the right to use the Test for the Limited Purpose described above.

In consideration of the mutual covenants and promises expressed herein and other good and valuable considerations, it is agreed as follows:

2) LICENSE

PAR hereby grants to Licensee, subject to the terms of this Agreement, a non-transferable, non-refundable, non-exclusive license to place the Test on Licensee's Website for the Limited Purpose described in Section 1 above. Licensee agrees to hold secure and treat as proprietary all information transferred to it from PAR. Licensee shall carefully control the use of the Test for the Limited Purpose described in this Agreement. Licensee's use of the Test will be under the supervision or in consultation with a qualified psychologist or other qualified individual and consistent with the then current edition of the Standards for Educational and Psychological Testing published by the American Psychological Association.

Appendix C: Email for use of CHIP

David Kropff Feb 19, 2019, 2:04 PM

to mccubbinresilience

To whom it may concern,

My name is David Kropff, and i am currently working on my dissertation, which involves parental stress, parental coping, and marriage satisfaction when raising a child with a congenital heart defect. With your permission, I would like to respectfully utilize the Coping Health Inventory for Parents (CHIP) scale in order to assess parental coping for my study.

I look forward to hearing from you at your earliest convenience, and thank you in advance.

Respectfully,
David Kropff

Jason Sievers Feb 19, 2019, 4:15 PM

to me

David –

Attached is the CHIP measure and all of its information. If you translate the measure into a language other than English, please send us a copy. Let us know if you have any questions.

Respectfully,

Jason

Laurie "Lali" McCubbin, PhD
Jason A. Sievers, PhD
Hamilton I. McCubbin, PhD
Resilience, Adaptation and Well-Being Project

Appendix D: Email for use of ENRICH

David Kropff Sun, Apr 7, 8:48 AM (2 days ago)

Hello Dr. Fowers,

My name is David Kropff and i am currently working on my dissertation which involves parental stress, parental coping, and marriage satisfaction when raising a child with a congenital heart defect. With your permission, I would like to respectfully utilize the ENRICH Marital Satisfaction Scale in order to assess martial satisfaction for my study. I look forward to hearing from you at your earliest convenience and thank you in advance.

Respectfully,

David Kropff

Fowers, Blaine J Sun, Apr 7, 9:12 AM (2 days ago)

to me

Greetings,
You have permission to use the Marital Satisfaction Scale from ENRICH. I have attached a copy of the article that contains the scale items and the scoring procedure. There is a more up-to-date version available from PREPARE/ENRICH.com, but you must participate in the PREPARE/ENRICH training to use it. You can contact them through their web site (prepare-enrich.com) if you want to use the most current version.

Best wishes,
Blaine

Blaine J. Fowers, Ph.D.