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Coping Challenges and Methods Among Parents of Children with Corpus Callosum Disorders

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Walden University
2019

Abstract

Coping Challenges and Methods Among Parents of Children with Corpus Callosum Disorders

Peggy A. Henninger

MA, University of Colorado, 1992

BA, Colorado State University, 1984

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Walden University

May 2019

Abstract

Disorders of the corpus callosum (ADCC) present developmental challenges to children and adults. These disorders are characterized by symptoms of abnormal behaviors and/or thinking patterns. Because ADCC may exist in combination with other disabilities, individual IQs and the severity and problems vary from individual to individual. Using the double ABCx model of family adaptation to stress related to a family member with a disability, the purpose of this cross-sectional study was to provide the first evaluation of parental adaptation among parents of children with ADCC. The final sample, 265 mothers of children with ADCC, was recruited through online support groups for ADCC parents. Parent adaptation was operationally defined as quality of life and operationalized by scores on the World Health Organization (WHO) Quality of Life Questionnaire (QOL). The predictors were measured by the Questionnaire on Resources and Stress (QRS), Family Empowerment Scale (FES), Sense of Coherence Scale (SOC), and Coping Health Inventory for Parents (CHIP). Linear regressions were used to evaluate the predictors in the 4-factor double ABCx prediction model of parent adaptation. Except for parent stress level, family empowerment, sense of coherence, and coping styles were statistically significant predictors of parental quality of life. That is, mothers who reported experiences of empowerment, coherence, and positive coping also have high self-reported quality of life. The findings, the first for experiences of parents of children with ADCC, provide valuable information for further research, but also for other parents and those who may be instrumental in the development of supportive services for this population.

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Dedication

To my husband, Michael Henninger, for always believing I'm better than I am, and supporting me through all of my journeys, especially this big one. I always love you more and would be nothing without you in my life! Someday soon, you can retire while I support you (for a change)!

My wonderful children: Bethany, Christopher, Sydney, and Tyler, who made me want to be the best mom always, and encouraged me to be a better person, with a Doctorate. I'm sorry for everything I missed, but you are always in my heart and on my mind, even while I was working on this.

To my brother, Rick Johnson, who gave me the confidence to be the first PhD in our family. To my baby brother, and parents, who I hope are enjoying this from heaven!

To my amazing friend, Meri, who never let me quit and promised pink beaches when we graduate together after crying and laughing through this. Wonderful Søs, you kept saying, "The chapter you already finished was the hardest one!" (Ha!) My patient and resourceful friends, Patty and Denise, that said, "PhD? Why not? You're only 50!"

For all the rest of my friends and family that have supported and loved me while I've been working on this PhD after I turned 50, when I was missing out on time with you and feeling guilty, no matter what I was doing, thank you for understanding.

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Sarah Calman, you are an inspiration to parents with children with ADCC worldwide, and I thank you for your guidance to these wonderful parents who completed my surveys with their heart and souls.

Dr. Shauna Casement, my role model and my idol. Thanks for your support and love through this experience. You are one of the biggest reasons I FINISHED THIS. Thank you.

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Chapter 1: Introduction to the Study

Introduction

When children are born with a corpus callosum disorder (ADCC), the 200 million nerve fibers in their brain's commissural pathway are partially or completely missing (Badaruddin et al., 2007). Badaruddin et al. (2007) summarized that children with ADCC are not easily categorized, as the range of social, behavioral, and cognitive outcomes vary as well as the differing combinations of disabilities and individual IQs that may also be present. Individuals with autism (ASD) have been compared to individuals with ADCC and have behavior similarities (Paul, Corsello, Kennedy, & Adolphs, 2014). To date, there have not been any studies of the parents of the children with ADCC examining their perceived stress, resources, sense of coherence, and coping skills leading to their perception of their quality of life. Therefore, the focus of this study was to gain information regarding stressors, social cognitions, and functioning of parents who are raising and caring for a child with ADCC.

The goal was to evaluate parents' self-reported experiences of stress, attitudes regarding resources, sense of coherence, and coping responses as a means to predict their experiences of quality of life (an indicator of family adaptation). ADCC is an uncommon neurological disorder, and parents are often unsure of the outcomes for their child due to differing opinions in medical, academic, and social areas. Programs might be made available if discussions create awareness of an unmet need. In this chapter, the background of ADCC is discussed, a problem statement is presented, the purpose of this study expressed, and the research questions/hypotheses given.

Background

Summary of Relevant Research

There have been many studies of stress and coping among parents of children with ASD (McStay, Trembath, & Dissanayake, 2014). The double ABCx model (McCubbin & Patterson, 1983) has been used to research intervening processes between an external stressor (e.g., child's disability) and the adaptation of the family to that stressor (xX). In particular, the intervening processes include perceptions of the stress experiences in relation to the stressor (aA), perceptions regarding resources available (bB), understanding and sense of coherence about the situation (cC), and coping processes (BC). Perceived quality of life is one example of a dimension of adaptation (see Figure 2 in Chapter 2 for summary of the model). Similar to previous models of stress and coping (Lazarus & Folkman, 1984; McCubbin & Figley, 1983), it was assumed that each parent in the same situation may perceive stress and resources, understand and engage, and cope differently, thereby experiencing different levels of quality of life. As stressors are ongoing, coping and adaptation is a continuous process and may vary across time.

Previous work to understand family adaptation among parents of children with ASD serves as a foundation for research in adaptation among parents of children with ADCC. ASD and ADCC are similar because both affect the brain and how the person interacts with his or her world. Parents who have children with ASD report that their prominent concerns involve their child's behaviors, particularly involving interactions with others (Mount & Dillon, 2014). Individuals with ADCC often have similar problems with behavior involving interactions, but the difficulties are not predictable and tend to vary by case (Paul et al., 2007). Further discussions of relationships between ASD and ADCC are presented in

Chapter 2. To examine processes of adaptation among parents of children with ADCC, I conducted a quantitative, cross-sectional online survey that measured each of the intervening variables identified in the double ABCx model using instruments that have been employed by others in similar research. In particular, the perceptions of stress (aA) using three subscales of the Parenting Stress Index-Short Form (Parental Distress, Parent-Child Dysfunctional Interactions, and the Difficult Child subscales) were operationalized (Abidin, 1995). The Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992) was used to assess the family's perceptions regarding resources and their own control over family, service system, and community resources (bB). The Sense of Coherence Scale (SOC; Antonovsky, 1987) was used to evaluate cognitive appraisal (cC) for how parents understand/make sense of the situation (Cc). I administered The Coping Health Inventory for Parents (CHIP; McCubbin et al., 1983) to identify parental coping. All of these factors and coping methods are conceptualized in the double ABCx model as predictors of adaptability of the parents (X). For this study, the indicator of X was perceived quality of life, which was assessed by the Quality of Life Questionnaire created by the World Health Organization (WHOQOL, 1994a). This assessment was used with parents of ASD and concluded that the more severe a child's disability, the lower the parents' score is in social and environmental areas of quality of life (Shan Leung & Ping Li Tsang, 2003).

Gap in the Literature

Although there have been numerous studies of stress and coping among parents of children with ASD, scholars have not examined parents of children with ADCC. More specifically, the double ABCx model of family coping (McCubbin & Patterson, 1983) has not yet been assessed with parents of children with ADCC. The reasons for

underrepresentation in research of this population may be related to the incidence rates and diagnostic process for identifying ADCC. Although prevalence figures vary, ADCC is estimated to be present in 1-4 out of 1,000 live births, with colossal disorders accounting for 2-3% (Badaruddin et al., 2007). ADCC may be underdiagnosed due to the need for extensive neuroimaging, usually an MRI, for verification. ADCC is not always visible externally, so it sometimes requires extra effort to advocate for and understand the needs of these parents and there is much remaining to be done in order to understand stress and coping among parents of children with ADCC. This study contributed to this gap in understanding and expanded the attention deserved to meet the treatment and support needs of these parents.

Problem Statement

The self-reported experiences of stress, resources, sense of coherence, and coping strategies may predict self-reported experiences of quality of life among parents of children with ADCC. The factors suggested by the double ABCx model of family coping may be significant predictors of positive adaptation by this population. There are more people with ADCC than ever before. Knowledge is needed to understand the effect it has on the family and develop support for these individuals and families so that ADCC is not considered an uncommon diagnosis with professionals giving varying advice.

Purpose of this Study

The purpose of this cross-sectional, correlational, quantitative study was to examine experiences of stress, resources, sense of coherence, and coping strategies as predictors of quality of life among parents of children with ADCC. Parents of children with ADCC are underrepresented in research on coping and adaptation. This study addressed that gap in the professional literature. The results of this study may encourage more attention to, and

discussion of, issues regarding the needs of this population. Practical applications may be more focused responses to assist parents newly exposed to the crisis of having a child with ADCC.

Research Questions

Research Question 1. Does perceived stress as a parent of a child with ADCC (as measured by the Questionnaire on Resources and Stress QRS) predict parental quality of life (as measured by the WHO-QOL-BREF)?

$H_0 1$: Perceived stress as a parent of a child with ADCC does not predict parental quality of life.

$H_1 1$: Perceived stress as a parent of child with ADCC does predict parental quality of life.

Research Question 2. Does parental experience of empowerment for care of a child with ADCC (as measured by the FES) predict parental quality of life (as measured by the WHO-QOL-BREF)?

$H_0 2$: Parental empowerment for the care of their child with ADCC does not predict parental quality of life.

$H_1 2$: Parental empowerment for the care of their child with ADCC does predict parental quality of life.

Research Question 3. Does parental sense of coherence (as measured by the SOC predict parental quality of life (as measured by the WHO-QOL-BREF)?

$H_0 3$: Parental sense of coherence does not predict parental quality of life.

$H_1 3$: Parental sense of coherence does predict parental quality of life.

Research Question 4. Does parental coping (as measured by the CHIP) predict parental quality of life (as measured by the WHO-QOL-BREF)?

$H_0 4$: Parental coping does not predict parental quality of life.

$H_1 4$: Parental coping does predict parental quality of life.

Research Question 5. Is a statistically significant proportion of the variance in parental quality of life (as measured by the WHO-QOL-BREF) explained by considering multiple predictors (perceived stress, QRS; family empowerment, FES; sense of coherence, SOC; and coping, CHIP)? What is the relative contribution of each predictor? Linear regression analyses were used to test each of the research hypotheses.

Theoretical Framework

The theoretical framework that was used for this study was the double ABCx theory by McCubbin and Patterson (1983). The external stressor was the disability (ADCC) of a member of the family, aA was the stress the family perceives, bB were the resources the family has, cC was the coherence appraisal, BC were the coping strategies the family has, and xX was the family's adaptations or perceptions of their quality of life. This theoretical model has been applied with success to families with children with ASD, and because symptoms, needs, and behaviors of both disorders are similar and have been reported to be a significant stressor for parents, it will be important to transfer this framework to parents of children with ADCC.

Nature of the Study

The double ABCx model has been used in studies to determine parent's stress and adaptation with children with ASD (McStay et al., 2014; Paynter, Riley, Beamish, Davies, & Milford, 2013; Pozo, Sarriå, & Brioso, 2014; Stuart & McGrew, 2009). Because children

with ASD and ADCC have similar behaviors, and these behaviors tend to increase a parent's stress, the double ABCx model aligned with this study. The (Aa) in the study was perceived parent stress measured by the Parenting Stress Index-Short Form 4 (Abidin,1995); (Bb) was the parent perceived resources measured by the FES (Koren et al., 1992); (Cc) was cognitive appraisal of the parent as measured by the SOC (Antonovsky, 1987); (BC) coping strategies as measured by

 the CHIP (McCubbin et al., 1983); and the family's adaptation measured by the Quality of Life (World Health Organization, 1996). The parents were recruited from the Agenesis of the Corpus Callosum Facebook page and were directed to take the surveys indicated that were on FreeOnlineSurveys. The data from the surveys were analyzed on SPSS (version 25).

Definitions

Adaptation/coping: The process of restructuring family characteristics to adjust to the impact of major life stressors and strains (Patterson, 1988).

Agenesis of the corpus callosum: A neurodevelopment disorder that can result from genetic, infectious, vascular, or toxic causes that are complete or partial (Sotiriadis & Makrydimas, 2012). Symptoms may include the complete or partial absence of the connective fibers between the left and right hemisphere of the brain that may increase epilepsy, deficits in handgrip, manual dexterity, crossing the midline, memory, and coordination (National Organization for Rare Disorders, 2007; Pacheco, Queiroz, Niza, Resende da Costa, & Ries, 2014).

Autism spectrum disorder: Neurodevelopmental disorders including impairments with social interactions and communication with others (Maenner et al., 2014).

Disability: To have some kind of condition that presents itself when a person tries to perform a routine activity (reading, speaking, walking, etc.) and has difficulties completing the task in a familiar way (Dunn, 2015).

Family crisis: A response within a family system that usually results from a loss of some kind, followed by pain of intensity equated with meaning invested (Maloney, 1971).

Quality of life: Degree of satisfaction with family interactions, parenting, emotional wellbeing, physical/material wellbeing, and disability-related support in families (WHO, 1996).

Stress: How a body reacts to a positive or negative situation (Selye, 1976).

Assumptions

I assumed that volunteer participants were actual parents of children with ADCC, were working alone and expressing only their own actual feelings and thoughts, understood the instructions and wording of the questionnaire items, and had sufficient understanding to manipulate an online survey.

Scope and Delimitations

The scope and delimitations to this study were that participants were volunteers who self-described as parents of children who had been diagnosed with ADCC. The sample was drawn from parents who were active in groups for parents of children with ADCC and had access to the Internet and are available for the online survey.

Limitations

Key limitations were that a convenience sample was used, namely those who volunteered. Further, recruitment was limited only to individuals who belonged to the target organizations and had access to computers and the Internet. These recruitment procedures

can limit generalizations of findings to parents of children with ADCC who do not fall into this online population and/or do not belong to these or other ADCC organizations. Also, it was unknown if a volunteer sample adequately represents nonvolunteers. The length of the survey also may be problematic for some individuals and affect their completion and/or thoroughness of responses.

<p style="text-align:center">Significance</p>

I offered the first known examination of stress, coping, and adaptation of parents of children with ADCC. The act of studying this group begins the conversation. The study findings may offer insights regarding factors that may enhance or hinder adaptation and quality of life among this special group. This information may lead to applications that can enhance support of these parents and families in medical, educational, and social settings. Acknowledgement of their situations may also help these parents engage with these systems without fear of being ostracized or misunderstood. In addition, it may help professionals, who may be better able to understand what these families need to move forward and achieve their own quality of life as well as their children's.

<p style="text-align:center">Summary</p>

Chapter 1 included an overview of this study. An overview was provided regarding ADCC, background, clarification of the gap in the literature to be addressed by this study, the problem statement, purpose of the study, research questions, the theoretical framework, nature of the study, definitions, assumptions, scope and delimitations, limitations, significance, and summary. In Chapter 2, I present an in-depth review of the relevant literature from which the specifics of the study are developed.

Chapter 2: Literature Review

Introduction

The corpus callosum is an anatomical and functional connection between the two cerebral hemispheres of the brain. It allows for higher order neurological advantages. The corpus callosum is responsible for transmitting and integrating sensory, cognitive, and motor information across the two hemispheres of the brain (Pacheco et al., 2014). Although development and functioning of the corpus callosum proceed within normal ranges for the majority of humans, disorders, specifically ADCC, are estimated to range from 1 per 19,000 (Kamnasaran, 2005), to as high as 1 per 1,000 of the population (Pacheco et al., 2014). ADCC is a defect of the brain where 200 million axons of the corpus callosum are partially or completely nonexistent (Badaruddin et al., 2007).

Although work has been done with parents of children with other neurological disorders, such as autism spectrum disorders (ASD), scholars have not examined parents with children with ADCC and how they navigate through educational, medical, and psychological labyrinths for their children and themselves. In this study, I focused on processes suggested by the double ABCx model of family adaptation. Following previous research by McStay et al. (2014) with mothers and fathers of children with ASD, I examined perceived stress, resources, sense of coherence, and coping as predictors of quality of life in parents of children with ADCC.

Scholars (Delongis, Coyne, Dakof, Folkman, & Lazarus, 1982; Folkman & Lazarus, 1986) created a social cognitive theory to consider how cognitive processes of appraisal guide coping and reactions to life events. Other theories and models followed that targeted coping as an adaptation within families of children with disabilities, in particular, Hill's

(1949) ABCx model of family stress and crisis. An expansion of Hill's model was followed by Lavee, McCubbin, and Patterson's (1985) double ABCx model of family stress and adaptations. To date, these theories have not been applied to the study of coping and adaptation in families of children with ADCC.

The double ABCx model of family crisis and adaptation was the theoretical framework for this study. Using this model, I investigated the following: the stressors of raising and caring for a child with ADCC and how their self-reported experiences of stress, resources, sense of coherence, and coping responses predicted their self-reported experiences of quality of life (an indicator of family adaptation). If there is better understanding of which components of this model are the best predictors of good family adjustment, those components can be targeted more directly for support and intervention.

In this chapter, I present existing literature regarding parents' challenges in coping and adjusting to children who have ADCC, as well as for parents of children with relatively comparative conditions, in particular, ASD. The chapter is organized to present the literature search strategy; the theoretical foundation; and reviews of background literature on corpus callosum disorders, similarities and differences between ASD and ADCC, and coping methods among parents of children with ASD. In addition, I identify gaps in the understanding of coping and adjustment among parents of children with ADCC and help to clarify the research questions that this study attempted to answer. Finally, there is a summary of Chapter 2 and transition to Chapter 3.

Literature Search Strategy

The literature review was compiled from several databases within the library of Walden University: PsycInfo, PsycExtra, PsycBooks, PsycCritiques, SocIndex, PsycTests,

Neuroscience, and Neuroradiology. The primary keywords used for searches were *disability, disorder, stress, difficulties, lifelong, handicap, parent stress, parent coping, development, brain, neuro, agenesis of corpus callosum, callosum, neurodevelopment, prenatal ACC, ACC, DCC, ADCC, dysgenesis, neuro disorders, and parent support, autism, parents of children with autism, parents of children coping with disabilities*, and *parents of children with corpus callosum disorders*.

Theoretical Foundation

Perhaps one of the best-known theories of coping is that of Lazarus and Folkman (1984), who described coping as a process in response to situations where internal and external demands may exceed the individual's resources. Folkman, Lazarus, Dunkel, Schetter, DeLongis, and Gruen (1986) determined that there are two major functions of coping. The first function of coping is trying to make sense of the stressor/problem, and the second function is to regulate the emotions that are occurring because of the stressor. Lazarus and Folkman (1984) explained that coping depends on cognitive processes, in particular, primary appraisal (What is the challenge?), and secondary appraisal (What are my options?). These initial cognitive processes portend coping strategies and behaviors that affect adjustment to the stressor. Hill's ABCx model is summarized in Figure 1.
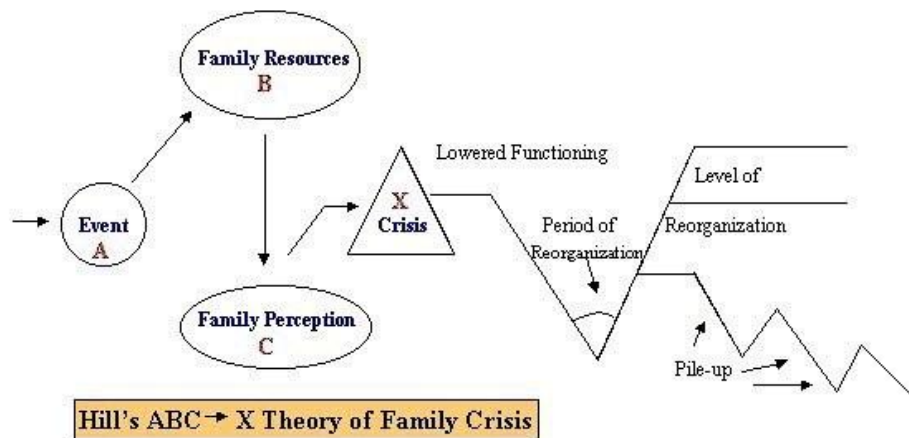
Figure 1. Hill's ABC->X Theory of family crisis. Adapted from, *The ABCX Formula and the Double ABCX Model*, by R. Hill, 2016, Retrieved from http://gozips.uakron.edu/~david27/Classes/fc/fcnote7.htm.

The above figure of Hill's ABC model of family crisis illustrates how families cope with a crisis when presented with one. (A) represents an event, (B) family resources, and (C) represents the family's perception when presented with a crisis (X) (Hill, 2016, p.1). Understanding this model could be valuable in developing supportive interventions, to reduce negative impact on families when confronted with an acute crisis.

Other theoretical frameworks of coping have been proposed that expand the hypothesized relationships among stressor, cognitive appraisals, coping, and ultimate adjustment. Of particular interest to the current area of inquiry are the ABCx model (Hill, 1949, 1958), and the double ABCx model (McCubbin & Patterson, 1983, 2008). Both of these models focus on families dealing with stressors, such as a disabled child. According to Hill (2016), both environmental factors (the event, family resources) and cognitive factors (family perceptions) were predictive of family functioning in response to ongoing crises.

The double ABCx model (McCubbin & Patterson, 1983, 2008) incorporates coping and sense of coherence as elements in predicting positive adaptation. The double ABCx model includes four categories of mediators between the external stressor (the child with the disability, other external life circumstances) and the family's level of adaptation: the amount of stress experienced by the parents, the parents' perceptions of available resources, the parents' appraisals of their ability to function as an effective family, and the parents' styles of coping. McCubbin and Patterson (2008) asserted that families work through stages of adaptation that have been labeled resistance, restructuring, and consolidation. McCubbin and Patterson viewed adaptation as dynamic, changing over time. Elements of A, B, and C are also thought to interact. For example, current perceptions of resources may affect current levels of stress, levels of stress may impact parents' appraisals of their ability to function, and each of these may impact and be impacted by coping strategies.

The double ABCx model has had support over the years (Saloviita, Italinna, & Leinonen, 2003). Lustig and Akey (1999) found that social support as a resource (B) and appraisals of sense of coherence (C) accounted for 47% of the variance in coping for families with an adult with intellectual disability. Some differences were found as it relates to the experience of the mother versus the father. For example, the relationship experience with the child is a greater stressor for fathers, while personal support is a greater stressor for mothers (Krauss, 1993). Beckman (1991) also found that fathers may experience more problems with attachment to the child while mothers are plagued with a sense of competence as a parent, as well as their relationship with their mate. Figure 2 (below) demonstrates how the stressor can affect every situation the parents are involved in.
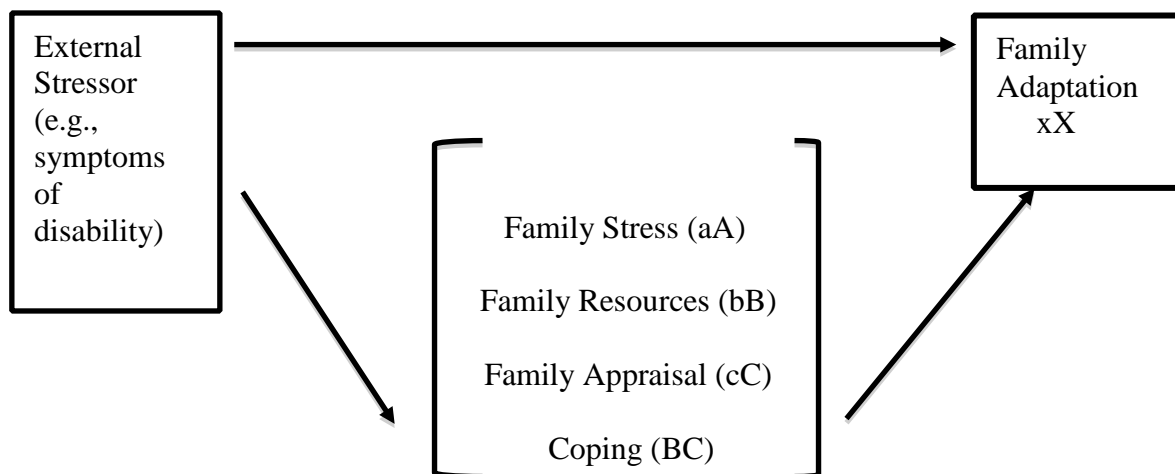
Figure 2. Adaptation of double ABCx model of family adaptation. Adapted from *Stress and the family: Coping with normative transitions,* 86, H.I. McCubbin & C. R. Figley, 1983a, New York: Routledge Taylor and Francis Group. Copyright 2002 by Sage Publishing. Adapted with permission.

The ABCx model of family adaptation is based on the evaluation of factors A through C as mediators between external stressor and family adaptation (xX) (McCubbin & Patterson, 1983). For example, parents with a child with ADCC is the external stressor, which is affected by the family's level of stress (aA), family resources (bB), family appraisal (cC), and ability to cope (BC) with this external stressor, which then leads to level of family adaptation to it (xX) (McCubbin & Patterson, 1983).

McStay et al. (2014) studied parents of children with ASD and found that "For mothers, child externalizing behavior, and difficulty seeing stressors as a challenge were the strongest predictors of stress; however, for fathers, lower coping is associated with greater stress level" (p. 3,113). Thompson, Hiebert-Murphy, and Trute (2012) found that mothers perceive self-esteem and positive appraisal as the successful connections between parenting

stress and family adjustment, while fathers did not perceive those as important factors. To date, no studies have applied the double ABCx model to parents of children with ADCC.

Literature Review

According to Dunn (2015), the term disability means to have some kind of condition that presents itself when a person tries to perform a routine activity (reading, speaking, walking, etc.) and has difficulties completing the task in a familiar way. Dunn explained that when people are adjusting to a diagnosis of a disability, there is either a coping (a positive perception) or succumbing (a focus on the negative) framework that becomes their belief system. It is the natural tendency for humans to make sense out of experiences (Baumeister & Vohs as cited by Dunn, 2015). Dunn also indicated that "finding positive meaning in a negative experience helps people cope with physical and emotional transformations and can be indicative of successful adjustments" (p. 83). Dunn and Burcaw (2013) identified communal attachment as being a link to an affirmation of a disability. When a person is diagnosed with a disability that is not common, such as a ADCC, they are only beginning to understand how the presence of an uncommon disorder has kept people isolated for so long (National Organization for Disorders of the Corpus Callosum, 2016). When one member of a family has a disability, it can be isolating for the whole family. Therefore, having support available can assist with coping and help to buffer some of the difficulties that arise (Marshak, Seligman, & Prezant, 1999).

Stress can be positive or negative, and it is inevitable if someone belongs to any kind of family or group. Stress can mean changes, even if a family's changes are expected, such as the birth of a child. Nonetheless, the family is required to adjust and adapt. Change is a part of a developmental process (McCubbin & Figley, 1983). Parents have many emotions when

they receive the diagnosis of a disability pertaining to their child. Some of those emotions are grief, denial, anger, depression, acceptance, and/or empowerment. Parents move through these motions at different times and at different rates throughout the process of parenting (Thomas, Dowling, & Nicoll, 2004).

Siman-Tov and Kaniel (2011) determined that life presents demands on individuals and families that create stress. Siman-Tov and Kaniel also clarified that the way a stressor is perceived determines the cognitive appraisal of the situation and initiates the person's coping ability. Autism and corpus callosum disorders are not readily visible so parents may be met with uncertainty and remain unsupported when they suspect something, compared to more symptomatic, visible disorders. The disability is the stressor but being unable to get validation and support creates the triad (the ABCx model) with varied processes of appraisal and control that generate positive parenting in difficult life situations. Parenting a child with a disability can be a positive experience that enhances personal and spiritual growth (Stainton & Besser as cited by Hall, Neely-Barnes, Graff, Krcek, & Roberts, 2012). Positive appraisals, having resources and support, developing the ability to engage in problem solving, and using coping strategies create family resiliency (Hall et al., 2012).

Lazarus and Folkman (1984) described coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of that person" (p. 141). Lazarus and Folkman clarified that coping is not automatized adaptive behavior; rather, it is related to what a person thinks or does, which means that there is a process to coping.

Disorders of the Corpus Callosum

The corpus callosum is a connective bundle of 200,000,000 to 350,000,000 fibers that pass between the two cerebral hemispheres of the brain (Kamnasaran, 2005; Pacheco, Queiroz, Niza, Costa, & Ries, 2014). At least 46 malformation syndromes and metabolic disorders have been discovered in patients with complete agenesis or hypoplasia (partial/dysgenesis) of the corpus callosum (Kamnasaran, 2005). The incidence of corpus callosum disorders has not been well defined (Marszal, 2000). In 2014, it was estimated that one in every 1,000 children may have a corpus callosum disorder, but because neuroimaging is not a commonly scheduled procedure, the true prevalence is unknown (Pacheco, 2014).

Disorders of the corpus callosum are associated with a chromosomal malformation (Lau et al., 2012; Marszal, 2000). A person who is born with corpus callosum deficiencies is also susceptible to other physical or mental disabilities. The most common is epilepsy, which is prevalent in 50% of the persons studied (Pacheco, et al., 2014). Generally, persons with corpus callosum disorders have extreme deficits in handgrip, manual dexterity, crossing the midline, and coordination, and they need to have a multidisciplinary team of experts to provide early interventions that direct the patient toward functionality because this disorder cannot be cured. However, the disorder can now be detected intrauterine (National Organization for Rare Disorders, 2007; Pacheco et al., 2014).

Similarities and Differences between ASD and ADCC

In order to create a framework for studying parents of children with ADCC, research was considered that has examined coping among parents of children with ASD. ASD have numerous traits, one being structural brain malformations, including the corpus callosum; however, ASD usually involves multiple regions of the brain (Hall & Graff, 2012). Although

coping among parents of children with ADCC has not received attention, there is literature on coping among parents of children with ASD. The decision to use this literature as a model for understanding coping among parents of children with ADCC was made based on similarities between ASD and ADCC. Both are neurological disorders. In addition, both are developmental disorders that are identified in early childhood, have malformations in the brain, and are of unknown origins. Generally, there are not visible physical abnormalities with either ASD or ADCC. Children with ADCC, age 2-5 years, were found to mainly have sleeping problems, while older children with ADCC, age 6-11, were found to have problems with attention, social function, thought, and somatic complaints, but when compared to children with autism, they were less impaired in all areas (Badaruddin et al., 2007).

Children with ASD usually have behavior descriptors of communication differences; social skills abnormalities; and/or limited, repetitive, and behaviors that have varying intensity (American Psychiatric Association as cited by Lau et al., 2012). The causes of ASD are unknown, but it is probable that the origin is environmental or hereditary (Hall & Graff, 2012; Lau et al., 2012). The causes of ADCC are also unknown (Paul et al., 2007). Hall and Graff (2012) stated that in order to diagnose ASD, there must be a comprehensive medical; developmental history; parent or caregiver reports; teacher reports/observations; neuroimaging; diagnostic cognitive assessments; speech/language profiles; adaptive behavior records; and professional observations on social, communication, play, and interaction skills. As of 2012, it was estimated that one in 81 people have some form of ASD. *The Diagnostic and Statistical Manual of Mental Disorders* (*DSM–5*; American Psychiatric Association, 2013) combined autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified into the ASD category. With this

diagnostic approach, it is estimated that one in 68 people have ASD, which is 1% of the population (author, year). Parents with children who have ASD have expressed that their principal concerns primarily revolve around the child's behaviors, interactions, and lack of flexibility, which have caused parents to be mentally and physically tired, especially if support is not available or is minimal (Mount & Dillon, 2014). I stopped reviewing here due to time constraints. Please go through the rest of your chapter and look for the patterns I pointed out to you. I will now look at Chapter 3.

Persons with ADCC share similar behaviors to those with ASD, such as poor social skills, difficulty with insight and genuine relationships, inability to express emotions or empathize appropriately, and performance and verbal IQs are usually extremely different. Results of research by Paul et al. (2007) may provide groundwork for further explanations of difficulties observed among those with ADCC in cognitively recognizing associations between their behavioral decisions, and the consequences of these actions. Because the corpus callosum is the bridge that associates both hemispheres of the brain, it is possible that in order for one to relate choices to actions to consequences, the corpus callosum may be required. Paul et al. (2007) also compiled features of children with ADCC, such as facial asymmetry with craniofacial changes, broad fingers or toes, possible deafness, and cardiac defects; however, there is not a single list of signs and symptoms for every person with ADCC.

Coping among Parents of Children with Autism Spectrum Disorders

Parents of children with ASD are believed to display higher levels of stress than parents of children with other disorders (Pozo et al., 2014). Pozo, Sarria, and Brioso (2011) have described ASD as one of the most inhibiting disorders for a family to experience.

Compatible with the ABCx and the Double ABCx models of coping (Hill, 1949, 1958; McCubbin & Patterson, 1983), increased social supports were shown to help decrease parental stress among this group of parents (Pozo et al., 2014). Further, the perception of the problem determines the parents' ability to cope, and the sense of coherency determines the parents' comprehensibility, manageability, and ability to acquire higher meaning from the situation (Pozo et al., 2014).

Research with the Double ABCx Model of Family Coping

Essentially, the Double ABCx model of family coping may be summarized in Figure 2. When the parents are presented with the stressor of a child with a disability, the parents experience some level of stress, form perceptions of support, develop a cognitive understanding and meaning of the situation, and respond with coping strategies. Depending on these meditational responses, parents and families have better or worse adaptation and resilience to the demands with which they are faced.

External demands. The Double ABCx model of family coping begins with the assumption that there are external stressors. In cases where there is a member of the family with a disability, this becomes the focal stressor. However, the degree to which the disability creates *objective* demands on the family depends on the type and severity of the symptoms (learning disabilities, memory deficits, concrete thinking, etc.), which influence the nature of the resources, caretaking activities, acuity or chronicity of the demands, and other elements which define the nature of the stressor (educational needs not being met, medical difficulties, peer/family relationships, etc., Kamnasaran, 2005).

Experiences of stress (aA). Given that there are objective external demands, the Double ABCx model then assumes that it is how the parents react, which determines their

types and levels of adaptation. First, it is important to consider the stress that is experienced

by the parents. Essentially, different individuals may perceive the same stressor differently.

Thus, subjective stress is an important consideration for understanding family adaptation.

Research with parents of children with ASD has frequently employed the Parenting Stress

Index-Short Form (PSI-SF, Abidin, 1995) to quantify the variable. The PSI-SF is a screening

measure for evaluating the parenting system and focuses on three major domains of stress:

child characteristics, parent characteristics, and situational/demographic life stress (APA,

2016).

The PSI-SF has been used in a study by Boyd (2002) that determined that parents,

especially mothers of children with ASD, had higher levels of stress when their children had

more difficult behaviors, which made them feel less able to parent. Dardas and Ahmad

(2014) found that the stress of parents of children with ASD is directly related to their role as

a parent, and increased stress affected parenting competence. Hayes (2013) has defined

parenting stress as distress resulting from the role of parenting (Deater-Deckard, 1998, as

cited by Hayes, 2013). The PSI-SF includes three subscales of the nature of the stressor,

Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child, and has been

used for several studies of parents of children with disabilities. As noted earlier, the severity

of the limitations of the child with ASD predicts parental stress. Increases or decreases in

symptoms and needs can influence the level of stress among parents of children with ASD

(Hayes, 2013). The greater the limitations of the child's adaptive behavior levels, ability to

communicate, and capabilities to routinely complete self-care requirements, the greater the

stress levels of mothers of children with ASD due to the amount of daily caregiving demands

(Tomanik, Harris, & Hawkins, 2004). In addition, recent work by McStay et al. (2014) with

parents of children with ASD found that symptoms of externalizing behaviors were the most predictive of higher stress and lower family quality of life (FQOL), while social communication skills or those related to daily functioning did not reach significance as predictors of stress experienced by parents or their reported FQOL.

Resources (bB). Several types of resources have been studied to define this element of the Double ABCx model for parents of children with ASD. Examples include self-reports of family cohesion, social support, and family support (McStay et al., 2014). McStay et al. (2014) employed several measures to evaluate various dimensions of perceived support within a family system: (a) the Family Hardiness Index (FHI) to explore three dimensions of parents' perceptions of the dependability of the family as a resource: commitment, challenge, and control; (b) the Family Environment Scale (FES; Moos & Moos, 1986) to evaluate the levels of cohesion, expression, and conflict within the family; (c) the Dyadic Adjustment Scale (DAS; Spanier) to study satisfaction, consensus, cohesion, and affection expression within the dyadic relationship of cohabitating couples; (d) the Family Support Scale (FSS; Dunst et al., 2007), which measures self-reported helpfulness of support from formal (professional services) and informal (e.g., friends and family) sources in raising a child with ASD. Responses from the Family Hardiness Scale (FHS) provided the strongest predictors of stress and/or family quality of life for mothers and fathers.

Although studied less frequently, a family's sense of empowerment regarding their rights, competence, motivation, and ability to reach out to obtain and use formal (e.g., agencies and professionals) and informal (e.g., friends and family) resources on behalf of their child with a disability (Koren et al., 1992; Vuorenmaa, Halme, Astedt-Kurki, Kaunonen, & Perala, 2013), would appear to warrant further investigation with relation to

perceptions about resources within the Double ABCx model of resiliency and family adaptation. Surprisingly, little attention has been given to this factor although there is some indication that it is predictive of a family's level of resilience and adaptation. Weiss, MacMullin, and Lunsky (2015) found that empowerment served as a significant mediator between the level of the child's problem behaviors, and the experiences of distress among a sample of mothers of children with ASD. For example, Weiss, Cappadocia, MacMullin, Viecili, and Lunsky (2012) reported that acceptance and empowerment were statistically significant mediators between behavior problems of children with ASD and parent's mental health. The FES (Koren et al., 1992) specifically measures how parents perceive and evaluate their own control over resources (within their family, service system, and community) for adapting to the needs of a child with a lifelong disability.

Cognitive appraisal (cC). McStay et al.'s (2014) review of studies exploring the ABCx model of adaptation among parents of children with ASD illustrates various attempts to operationally define types of cognitive responses that parents may have in order to try to make sense of the situation: self-blame and catastrophizing, feelings of threat, and framing the implications (positive and negative) of raising a child with ASD. One of the key constructs associated with cognitive appraisal in the Double ABCx model involves the parent's sense of coherence (SOC).

Antonovsky (1987) developed the SOC, which has been used in numerous studies of the Double ABCX model of family adaptation. For example, Pozo, Sarria, and Brioso (2013) found that higher SOC is associated with higher family quality of life among parents of children (and adults) with ASD. Using a short form of the SOC by Sagy (1998), a colleague of Antonovsky, McStay et al. (2014) also found that SOC is a statistically significant

predictor, both of stress, and of family quality of life among mothers and fathers of children with ASD. The SOC involves three dimensions: (a) comprehensibility, seeing the world as structured, (b) manageability, expecting things to be manageable, and (c) meaningfulness, seeing life as meaningful (Sivberg, 2002).

Coping strategies (BC). The Double ABCx model (McCubbin & Patterson, 1983, 2008) assumes that coping strategies add another dimension to the process defining family resilience and adaptation. The Double ABCx model includes coping as the family's attempts to restore balance. When coping is effective, outcomes such as improved adaptation and higher quality of life ensue. When coping strategies are not as effective, outcomes are less positive. In fact, McCubbin and Patterson (1983, 2008) found that positive and negative coping strategies play a particularly significant role in understanding family functionality.

Various measures have been used to assess coping based on the Double ABCx model of family adaptation among parents of children with developmental disabilities. For example, Pakenham, Samios, and Sofronoff (2005) employed the COPE (Carver et al., 1989), which offers questions to evaluate dispositional styles of coping, time-limited responses, and degree to which they have been using various responses across a period of time. Plant and Sanders (2007) employed the Ways of Coping Questionnaire - Revised (WOC-R: Lazarus and Folkman, 1984) to study caretaker stress among parents of children with developmental disabilities. The WOC-R is useful for identifying thoughts and behaviors individuals use to respond to a specific stressor.

McStay et al. (2014) studied coping as a predictor of quality of life using the Double ABCX model quality of life for mothers and fathers of children with ASD. Their measure for coping is the Family Crisis Oriented Personal Evaluation Scales (F-COPES; McCubbin et al.,

1981). This measure assesses perceptions of parents regarding how the family unit copes. The measure evaluates five dimensions of coping, including acquiring social support, mobilizing to acquire and accept help, reframing, passive appraisal, and seeking spiritual support. McStay et al. (2014) found that the F-COPES scores significantly predicted family quality of life among mothers and stress among fathers of children with ASD. Responses are classified according to a particular coping type: confrontation, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planned problem-solving, positive reappraisal. Others (e.g., Gothwall, Bharani, & Reddy, 2015) have employed the CHIP (McCubbin et al., 1983).

The CHIP (McCubbin et al., 1983) was used in this study as it has been used in various situations when parents are coping with their child's disability or health on an ongoing basis. Having a child that has ADCC requires the parents to provide long-term care and manage family life daily. There are three subscales within the CHIP that are important to separate: (a) family integration, cooperation, and having an optimistic view of the situation, (b) maintaining social support, self-esteem, and psychological stability, and (c) understanding the health care situation through communication with other parents and health care professionals.

Adaptation (xX). In the Double ABCx Model, adaptation may be defined through such outcome variables as quality of life or other indicators. McStay et al. (2014) selected the Family Quality of Life Survey (FQOL; Hoffman et al., 2006) for their assessment of quality of life as an indicator of adaptation among mothers and fathers of children with ASD. The measure evaluates the degree of satisfaction with family interaction, parenting, emotional wellbeing, physical/material wellbeing, and disability related support. Importantly, rather

than the individual's quality of life, it inquires as to the quality of life based on how the family unit has adapted.

The Quality of Life Questionnaire was created by the World Health Organization (WHOQOL, 1994) to guide practitioners in defining subjective individual's perception of their quality of life that can be used throughout the world. It is apparent that a person's belief systems regarding their physical health, psychological state, independence, social relationships, and beliefs about their relationships within their circumstances and environment affect their wellbeing, and their abilities to parent children with developmental diseases (Mugno, Ruta, D'Arrigo, & Mazzone, 2007). Dardas (2014) and Dardas and Ahmed (2014) completed research among parents of children with ASD to determine their level of stress, coping strategies, and their perceived quality of life. It was found that the more severe a child's physical or mental disability, the parents scored lower on the WHOQOL, especially in social and environmental domains due to the demands put upon the parent (Shan Leung & Ping Li-Tsang, 2003).

Practical Benefits of Studying Families' Adaptation

While evaluating the validity of a theoretical model is a valuable motivation for research with parents of children with disabilities, it is important to consider how this research with groups of parents has practical, social significance. In the clinical setting, the Double ABCx model may be applied for conceptualizing a family's needs, and planning interventions that can focus on strengths and respond to these assessments. For example, Xu (2007) offers a report of an actual application of the Double ABCx model for two culturally diverse families with young children with disabilities. Xu described a process that may be used by professionals: Step 1 (aA): observe and identify the primary stressor and others that

accumulate along with it; Step 2 (bB): identify existing resources the family has used to cope, and those that are still needed, and work with the family's own situation (e.g., attitudes, accessibility), to develop plans and strategies for obtaining more resources; Step 3 (cC): examine and re-examine family perceptions across the process, recognizing that "perceptions are dynamic, especially where multiple variables are involved" (p. 436); Step 4: empower families with effective coping strategies (xX).

Summary and Conclusions

This review of the literature has highlighted the utility of the Double ABCx model for understanding processes of resilience and adaptation among parents of children with disabilities, in particular, parents of children with ASD. However, there was a stark dearth of research regarding the challenges and adaptation of parents of children with ADCC, in general, and in relation to the Double ABCx model of adaptation.

The proposed study did respond to the gap in the literature by surveying parents of children with ADCC. In particular, this study focused on processes suggested by the Double ABCx model of family adaptation. Following previous research by McStay et al. (2014) with mothers and fathers of children with ASD, this study examined relationships between the environmental stressor and the parents' reports of family quality of life, considering the mediating roles of the parents' experienced stress, perceptions of resources, cognitive appraisals, and coping. The research questions along with the quantitative, cross-sectional, correlational survey design that followed from the Double ABCx model of family adaptation was detailed in Chapter 3.

Chapter 3: Research Method

Introduction

The purpose of this study was to gain information regarding the stressors, social cognitions, and functioning of parents who are raising and caring for a child with ADCC. In particular, the goal was to evaluate their self-reported experiences of stress, attitudes regarding resources, sense of coherence, and how coping responses predict their experience of quality of life (an indicator of family adaptation). The double ABCx model of family crisis and adaptation (Lavee et al., 1985) was the theoretical framework for this study. Although previous scholars focused on parents of children with other medical challenges, such as children with autism, this was the first known study on parents of children with ADCC. If researchers better understand which components of this model are the best predictors of stress, better or worse, in relation to family adjustment, those components may be targeted more directly for support and intervention for parents of children with ADCC. In this chapter, I present the research questions to be addressed, as well as the research design and rationale, the sample and sampling procedures, instrumentation and operationalization of the constructs, possible threats to the validity of the design, ethical procedures, and a chapter summary.

Research Design and Rationale

I used a quantitative, cross-sectional, correlational design that assessed a predictive model of family functioning based on the Double XYZ model of parental stress and functioning. The predictor variables included parents' self-reported experiences of stress, attitudes regarding resources, sense of coherence, and coping responses. The dependent variable was quality of life, an outcome variable.

In 1983, McCubbin and Figley developed the Double ABCX theory regarding families coping with stress. More recently McStay et al. (2014) researched the quality of life of parents with children having AS) using the double ABCX model. There are multiple factors influencing a family, starting with the stress caused by the disability; the resources the family has; and the family's appraisal of their situation, their coping, and how they adapt to situations. Because ASD and ADCC are similar in behaviors shown by individuals who have them, and behavior of children is a primary stressor for parents (Hall & Graff, 2012), this model correlated well for this research. Given that parenting a child with a disability, such as ADCC, is a situation with a viable external stressor, I examined perceived stress in that situation, family resources, sense of coherence, and coping as predictors of quality of life among parents of children with ADCC (see Figure 2).

Methodology

Population

There is an incidence rate of 1 per 1,000 of the world population with ADCC (Pacheco et al., 2014). ADCC is a defect of the brain with the axons of the corpus callosum being partially or completely nonexistent (Badaruddin et al., 2007). The target population for inclusion criteria was parents with children who are 0- to 12-years-old and have been diagnosed with ADCC, can participate through social media (Facebook), and can understand and communicate in English on the Internet. The population that was sampled was mainly a Facebook group called Agenesis of the Corpus Callosum, established for parents with children with ADCC. There were 2,427 members in this group. Permission was obtained from the administrator of the group to post the survey online. The exclusion criteria included anyone that did not fit the inclusion criteria (above).

Sample and Sampling

I used convenience sampling. A G*power analysis was used to estimate minimum sample size. The planned statistical tests involved linear regression. Statistical significance was based on a fixed model and F-value evaluations for R^2 increases. The a priori power analysis with the following parameters: effect size = 0.15, error probability = $p \le .05$, power = .95, with a maximum of 12 tested predictors. The minimum related sample size to achieve the desired power was 184 participants. To be sure to have a sufficient number of useable surveys, at least 230 (184 + 25%) surveys were collected before closing the collection process.

Procedures for Recruitment

A recruitment announcement was posted on the Agenesis of the Corpus Facebook site. The announcement gave an explanation of the purpose of the study and a link to the survey site. A recruitment announcement and demographic questionnaire (Appendix A) were sent to participants that responded positively to the Facebook announcement. The survey was posted on Free Online Surveys. Free Online Surveys is an online survey tool allowing for easy completion and collection of data.

When a potential participant went to the survey site, the first page presented the informed consent form, as well as basic statements to inform possible participants of the inclusion criteria. At the bottom of the form, the individual was presented with three choices: to agree to participate (signifying informed consent), to choose not to participate, or to request more information before making a decision. Individuals who chose to participate were forwarded to the first page of the survey materials.

Anyone who chose not to participate was advanced to a "Thank you" exit page. Those who requested more information were provided with contact information, and an e-mail was sent to me with that inquiry. Once the participant entered the survey materials, being over age 18, male or female, and demographic information were the only records asked of the participant. After starting the questionnaire, the participant advanced to new page that gave instructions and questions for the QRS the FES (to analyze family resources), the Antonovsky SOC (to analyze family adaptation), the CHIP (to analyze the family's coping), and the 26-question WHOQOL-BREF (to analyze the family's adaptation). These forms took up to an hour to fill out so there was an option to save what was finished and log in at a later time to finish all of them. The different scales did not need to be titled and were separated into 5-question sections. Each time the participant got to the bottom of the five questions and answered all of them, there was a different encouragement quote. If there were any question unanswered, the participant was not able to go on until all questions were answered in order to decrease possible invalid returns. There were no follow-up procedures.

Instrumentation

The Questionnaire on Resources and Stress. The Questionnaire on Resources and Stress-Short Form (Holroyd, 1974) was developed to be a screening instrument to identify stress in families with a member who is disabled. Each statement is a true or false statement depending on the parent's perception. There were 66 items that were self-administered, true-false items divided into three general categories: (a) personal problems (consisting of poor health/mood, excess time demands, negative attitude toward index case, overprotection/dependency, lack of social support, overcommitment /martyrdom, and pessimism), (b) family problems (consisting of lack of family integration, limits on family

opportunity, and financial problems), (c) problems of index case (including physical incapacitation, lack of activities for index case, occupational limitations for index case, social obtrusiveness, and difficult personality characteristics). The reliability correlation was .96 for the total score of the categories, and Cronbach's alpha was .93 (Saloviita et al., 2003).

The Family Empowerment Scale. Koren et al. (1992) developed the FES to measure three factors reflecting different areas of a family's life where they are empowered or need support on behalf of a child/family member with special needs: (a) feeling empowered in their own home, (b) able to get what they need from the service systems available, and (c) the ability to maneuver and acquire their community needs. These separate scores are important to determine where parents feel most empowered and the areas they may need more resources to assist them. The FES has psychometric properties and may be useful in assessing the empowerment status of families whose children are handicapped (Singh et al., 1995). There are 34 statements and a scale from 1-5 for each statement: 1 = *never*, 2 = *seldom*, 3 = *sometimes,* 4 = *often*, and 5 = *very often*. Each subtest was scored by the mean of the totals within that set. Cronbach's alpha for each factor ranged from .867-.895 (Kageyama et al., 2016). Cronbach's alpha for the total of all subscales was .84-.90 (Vuorenmaa et al., 2013). The FES has acceptable psychometric properties and may be useful in assessing the empowerment status of families whose children are handicapped (Singh et al., 1995). The concurrent validity resulted in findings that parents who participated in service activities were empowered in school settings (Vuorenmaa et al., 2013). There were three separate scores for this scale so that it could be determined if a family feels empowered in their own home, if they are able to get what they need from the service systems available, and if they are able to maneuver and acquire their needs from the community. Separate scores, rather

than an average score, are important to determine where parents feel most empowered and the areas they may need more information to assist them.

Antonovsky's Sense of Coherence Scale. The SOC was developed to explain why people rate their wellbeing differently with the same amount of strain on each person. It has high test-retest reliability with $r = .92$, $p < .0001$ (Holmefur, Sundberg, Wettergren, & Langius-Eklof, 2015). There were 12 statements with a 1-7 rating scale for each statement (1 = *seldom*, *never through* 7 = *always, most*). This took about 5 minutes to complete. The three components of this scale were comprehensibility, manageability, and meaningfulness of a person's life. Test-retest reliability from 7-30 days was high with $r = .93$, $p < .0001$ (Frenz, Carey, & Jorgensen, 1993). The current Cronbach's alpha for total score was .88 (Al-Yagon, 2015). This was a one-of-a-kind scale that associated how well families adjust to their situations. The mean rating of all items was used for this study in order to determine the parents' overall outlook.

The Coping Health Inventory for Parents. The CHIP was developed in 1983 by McCubbin et al. as a 45-item parent questionnaire assessing a parent's perception of how they manage family life with a child with a chronic illness. The subscales are maintaining an optimistic family definition of the situation, the family stability, and understanding situations with medical staff and other parents. The test-retest reliability ranges from .68 to .86. Cronbach's alpha estimates for all items taken together ranged from .90 -.86 (Aguilar-Vafaie, 2008), and .79, .79, and .71 for each of the three subscales (McCubbin et al., 1983). This assessment took between 15-30 minutes to complete.

Quality of Life – BREF. The World Health Organization (WHO, 1994) developed the QoL-BREF assessment to be used cross-culturally to determine parental perception of

their lives in four domains: physical, psychological, social relationships, and their interactions with the environment. Parents were asked to answer questions focusing on their experiences during the last 2 weeks to maintain objectivity and specifics rather than subjectivity and generalizations. There were 26 questions that had ratings from 1 (*very poor*) through 5 (*very good*). Overall, Cronbach's alpha was .93 (Dardas & Ahmad, 2014). Internal consistency and reliability were rated good to excellent and were determined to be a good instrument for measuring QoL and needs in families with disabilities. Low QOL scores generally related to higher disability severity and greater behavior problems (Markowitz et al., 2016). Separate scale scores were computed for each of the four domains so that it was clear which areas parents perceived their positives and negatives.

Planned Data Analysis

Data from incomplete surveys or from participants not fitting eligibility requirements were excluded from analysis. Analysis was conducted in the following order:

Cleaning data. Data were visually inspected for data entry errors, and any errors were corrected. Using SPSS's (version 25) explore function, I identified missing values and outliers. Depending on the frequency/number of missing values for particular participants and/or particular questions, a determination was made to either delete the participant's data or use a method of imputation (e.g., substitute the missing value with the individual's mean rating for the scale). When the participant answered a question, the next question appeared, but when a question was left unanswered, the participant was not able to proceed to the next question, so that all questions were completely answered before the survey was finalized. The histogram and box plot for each scale's distribution of scores was inspected to identify values that were considered univariate outliers (i.e., more than 3 SDs beyond the mean score

for the distribution; Cicchetti, 1994). Unless an outlier appeared to be due to random responding or other error, the data from individuals who were more extreme were kept while also reducing the deviance from a normal distribution of scores. In those cases, the winsorizing method was used to convert the extreme value to a value within expected range of no more than 3 standard deviations from the mean (Cicchetti, 1994).

Sample demographics. The next step was to run crosstabs and descriptive statistics to describe the sample, based on the questions completed in the demographics questionnaire (Appendix A). Frequencies of membership in classifications (i.e., gender) and mean and standard deviation were reported for items with continuous responses (i.e., age).

Evaluating internal reliabilities of research measures. The Cronbach's alpha value was computed for each set of items that constitute a scale in this study. Those that had a minimum value of .70 were considered acceptable for the research sample.

Testing assumptions for statistical tests. Scale scores were computed for each of the variable's measures. Basic descriptive statistics was computed for each of the research variables (number, mean, standard deviation, skewness, and kurtosis). Linear and multiple linear regressions was used to test research hypotheses. The next test was to determine whether the data met the assumptions of the model. An initial assumption was that the dependent variable was continuous and normally distributed. First, it was assumed that the dependent variable for each regression analysis was a continuous variable that was normally distributed. To evaluate normality, I used SPSS to generate histograms, Q-Q plots, and the results of the Shapiro-Wilks test of normality. If the distribution was not normal, an appropriate transformation (depending on whether there was a positive or negative skew) was applied to approximate normality. If normality could not be achieved, the variable was

transformed to a discrete variable (nominal or ordinal), and an alternative nonparametric statistic (i.e., logistic regression) was used for testing hypotheses.

Second, linear regressions were based on bivariate correlations. The assumptions were that both variables were continuous scales of measurement, each variable was normally distributed, and there was linearity and homoscedasticity in the shape of the values when a scatterplot of the coordinates of the pairs of values was examined (points fall along a straight line; the scatterplot was oval shaped so that there was a range of paired values on both variables; Meyers, Gamst, & Guarino, 2013, p. 125). There are additional assumptions for multiple linear regressions (more than one predictor variable). These include multivariate normality, no multicollinearity, and homoscedasticity (Meyers et al., 2013, pp. 588-589). SPSS was used to evaluate multivariate normality by examining residuals (Q-Q plots) and goodness of fit (Kolmogorov-Smirnov test). The correlation matrix of all bivariate correlations (Pearson product-moment correlations) was examined to see if there were high correlations between predictor variables. Additionally, the tolerance (T<.01 suggests multicollinearity), variance inflation factor (VIF; VIF > 10 indicates multicollinearity), and condition index (strong multicollinearity was indicated with values >30) was computed. Homoscedasticity was evaluated by examining scatterplots. Transformations were applied as appropriate. Where assumptions could not be met, nonparametric alternatives (i.e., logistic regression) were applied.

Testing research hypotheses. Each research question and hypotheses are listed below, followed by the planned statistical test for that research hypothesis.

Research Questions

Research Question 1. Does perceived stress as a parent of a child with ADCC (as measured

by the Parent Stress Index (PSI-SF) predict parental quality of life (as measured by the

WHO-QOL-BREF)?

H_01: Perceived stress as a parent of a child with ADCC does not predict parental

quality of life.

H_11: Perceived stress as a parent of child with ADCC does predict parental quality of

life.

Research Question 2. Does parental experience of empowerment for care of a child with

ADCC (as measured by the FES) predict parental quality of life (as measured by the WHO-

QOL-BREF)?

H_02: Parental empowerment for the care of their child with ADCC does not predict

parental quality of life.

H_12: Parental empowerment for the care of their child with ADCC does predict

parental quality of life.

Research Question 3. Does parental sense of coherence (as measured by the SOC predict

parental quality of life (as measured by the WHO-QOL-BREF)?

H_03: Parental sense of coherence does not predict parental quality of life.

H_13: Parental sense of coherence does predict parental quality of life.

Research Question 4. Does parental coping (as measured by the CHIP) predict parental

quality of life (as measured by the WHO-QOL-BREF)?

H_04: Parental coping does not predict parental quality of life.

H_14: Parental coping does predict parental quality of life.

Research Question 5. Isa statistically significant proportion of the variance in parental quality of life (as measured by the WHO-QOL-BREF) explained by considering multiple predictors (perceived stress, PSI-SI; family empowerment, FES; sense of coherence, SOC; and coping, CHIP)? What is the relative contribution of each predictor?

H_05: Perceived stress, family empowerment, sense of coherence, and coping do not predict a statistically significant proportion of variance in parental quality of life.

H_15: Perceived stress, family empowerment, sense of coherence, and coping predict a statistically significant proportion of variance in parental quality of life.

A separate linear regression for each of the four components of Quality of Life (physical, psychological, social relationships, and their interactions with the environment) was employed to test each hypothesis. A regression analysis including all predictors was used to test Research Questions.

Threats to Validity

External - Sampling. The external threats to validity affect the degree to which results can be generalized to specific samples. Random sampling from the population would mean that every parent that has a child, 12 years old or younger, with ADCC would have an equal chance of participation in the study, which would support generalization of findings to other members of the population. Because the participants were volunteers, a convenience sample, generalizability of results cannot be readily assumed. At best, results may generalize to individuals who are connected to the Internet and belong to the ADCC Facebook Page. With that caveat, the results still had practical usefulness.

Internal Validity. Internal validity relates to the study's design. One possible threat was that this research used only one method and source of data, self-report surveys. There

were no other sources of information to corroborate the child's symptoms or the parents' responses. Another possible threat was that, for some reason, one or more of the surveys may not be reliable or valid for this particular population. These surveys have been chosen and assumed to be the best instruments to be appropriate for the variables for this population. These assessments have been used in various combinations with other parental groups, such as parents of children with ASD, but this was the first time used to gather information from parents of children with ADCC.

There was also an assumption that there was sufficient understanding and reading ability of the assessments, and access to parents with adequate exposure of their child with ADCC. Because there were a number of surveys, fatigue might have been a factor, and patterns of responses in letterform were considered. The parents may have stopped and restarted (with answers saved) many times as needed before the surveys were completed, in order to decrease fatigue. There was a concern that the carryover effect may occur when moving from one survey to another, so that when a participant answered a question, they could not go back and change answers.

Ethical Procedures

The study was designed to minimize risk of harm to any participants. All participants were presented with an informed consent prior to beginning the survey, and they were notified of their right to discontinue the study at any point and given the opportunity to contact the researcher or Walden University with any questions or concerns. There was no disclosure of confidential information. There was no intent to increase a participant's stress level. There was no unwanted solicitation, intrusion, or observation of participants. All answers were confidential to the researcher, chair and committee members, and no private

identifying information was used. Data integrity and confidentiality was used throughout this study.

Summary

The purpose of this study was to explore adaptive functioning (here, defined as quality of life) among parents of children with ADCC. Research questions that were tested followed from the Double ABCx model family adaptation for families with a child with a disability. Participants was recruited on social media, through a Facebook group of members who are parents of children with ADCC. Participants were asked to participate through an online survey. Ethical protection was provided for all participants. Results of the survey were reported in Chapter 4.

Chapter 4: Results

Introduction

The purpose of this study was to gain information regarding predictors of adaptation, as defined through QOL, among parents of children with ADCC. I used a quantitative survey design and linear regression analyses to examine individual predictors, as well as an overall prediction model, of QOL. The research questions and hypotheses were as follows:

Research Question 1. Does perceived stress as a parent of a child with ADCC (as measured by the Questionnaire on Resources and Stress, QRS) predict parental quality of life (as measured by the WHO-QOL-BREF)?

$H_0 1$: Perceived stress as a parent of a child with ADCC does not predict parental QOL.

$H_1 1$: Perceived stress as a parent of child with ADCC does predict parental QOL.

Research Question 2. Does parental experience of empowerment for care of a child with ADCC (as measured by the FES) predict parental QOL (as measured by the WHO-QOL-BREF)?

$H_0 2$: Parental empowerment for the care of their child with ADCC does not predict parental QOL.

$H_1 2$: Parental empowerment for the care of their child with ADCC does predict parental QOL.

Research Question 3. Does parental sense of coherence (as measured by the SOC predict parental QOL (as measured by the WHO-QOL-BREF)?

$H_0 3$: Parental sense of coherence does not predict parental QOL.

$H_1 3$: Parental sense of coherence does predict parental QOL.

Research Question 4. Does parental coping (as measured by the CHIP) predict parental QOL (as measured by the WHO-QOL-BREF)?

$H_0 4$: Parental coping does not predict parental QOL.

$H_1 4$: Parental coping does predict parental QOL.

Research Question 5. Is a statistically significant proportion of the variance in parental QOL (as measured by the WHO-QOL-BREF) explained by considering multiple predictors (perceived stress, QRS; family empowerment, FES; sense of coherence, SOC; and coping, CHIP)? What is the relative contribution of each predictor?

In Chapter 4, I present information about data collection, data evaluation, tests and results of the research hypotheses, and the summary of findings.

Data Collection

Data were collected according to the plan described in Chapter 3. Data were collected over a period of 34 days from May to June of 2018. Respondents were reached through biweekly Facebook posts and shares for parents of children with ADCC. Respondents were worldwide and were able to read and respond in English. The Facebook sites were Agenesis of the Corpus Callosum Awareness, The Gems of ACC, 2018, 2017, 2016, 2014 and 2015, 2013, 2012 ACC/DCC babies support groups, The Heroes of ACC, Agenesis of the Corpus Callosum, ACC Network/Listserv Alumni, Corpus Callosum Agenesis Denmark, Agenesis of the Corpus Callosum Sverige, The Phoenixes of ACC, Agenesis of Corpus Callosum Support, Friends and Family of kids with ACC, Moms of NODCC, Making a Connection: Agenesis of the Corpus Callosum, The Silver Butterfly: Agenesis of the Corpus Callosum, and Parents of Kids with Neurological Disorders.

There were no discrepancies in data collection from the plan presented in Chapter 3. Survey responses varied from zero to 20 per day. In total, 265 respondents initiated and completed the survey within the stated timeframe. Eligible respondents indicated they had a child with ADCC; the respondents who answered "no" were exited from the survey without being presented the actual survey questions. Because of HIPAA, if parents with children with ADCC were not on the Facebook pages (above) and voluntarily chose to participate, these parents are unknown and not able to be approached. Avoidance of harm to all participants was paramount in this study.

Characteristics of the Sample

All total, there were 265 eligible participants who completed all parts of the survey. Responses on the demographic questionnaire indicated that 100% were 18 years old or older, and all were female. Please see details in Table 1 for distributions by country of participant. No other demographics were collected.

Table 1

Demographics of Parent Participants

Country/Home	Number of Responses	Percentage %
Africa	2	0.70
Australia	17	6.40
Bosnia	1	0.30
Canada	12	4.50
Denmark	3	1.10
Great Britain	33	12.4
Greece	1	0.30
India	1	0.30
Israel	1	0.30
Italy	7	0.70
New Zealand	6	2.20
Romania	2	0.70
Singapore	2	0.70
Unknown	5	1.80
United States	177	66.7

Internal Reliability of the Measures

Cronbach's alpha is a measure that is used to determine the internal consistency of a set of test items. It is computed by correlating the score for each scale item with the total score for each respondent. It is calculated by the following: $\alpha = k \times c^- v^- + (k-1)c^-$ (k is the number of scale items, c^- refers to the average of all covariances between items, and v^- refers to the average variance of each item). If Cronbach's alpha had a value of .70 or higher, it was considered acceptable. Internal reliability of the research measures was examined for the current sample for this study. Table 2 presents a summary of computed Cronbach's alpha values for the measures in this study, and all scores were above .70.

Table 2

Internal Reliability Estimates for Research Scales

Scale	Number of Items	Cronbach's Alpha
QOL Physical Health	258	.785
QOL Psychological Health	258	.780
QOL Social Relationships	258	.789
QOL Environment	258	.788
QRS	258	.850
CHIP	258	.818
FES	258	.826
SOC	258	.822

Cleaning and Screening Data

Responses to the survey items were downloaded from the survey site to an Excel spreadsheet form. These values were transferred to an SPSS (v. 25) data file and variables were set up accordingly. Initial exploration of items indicated no missing values. The survey required a response to each item before it would advance. Scale scores were computed for each of the research variables by calculating the mean rating for each scale's items.

Outliers

After computing the scale scores for each of the research variables, I inspected the distributions of these scale scores using the SPSS v.25 explore function, and then checked for outliers within each of the separate scale scores' distributions. QOL had one outlier that was a low extreme, QRS had one outlier that was a high extreme, CHIP had two outliers that

were low extremes, FES had no outliers, and SOC had one outlier that was a low extreme and two that were high extremes. The outlier cases were eliminated from the data set.

Descriptive Statistics of Scale Scores

After correcting for outliers, descriptive statistics were computed for each of the research scales, including mean, standard deviation, skewness, and kurtosis. These values are summarized in Table 3.

Table 3

Descriptive Statistics for Research Scales

Scale	Mean	SD	Skewness	Kurtosis
QOL Overall	3.59	.560	-.050	-1.09
QOL Physical Health	3.19	.470	-.440	-.320
QOL Psychological Health	3.72	.580	.130	-1.01
QOL Social Relationships	3.92	.680	-.120	-1.09
QOL Environment	3.92	.380	-.520	-.520
QRS	.560	0.08	-.370	-.800
CHIP	2.08	.460	-.550	-1.27
FES	3.46	.820	-.060	-1.27
SOC	4.24	.390	-.060	-.230

Note. QOL = Quality of Life; QRS = Family Stress; CHIP = Coping; FES = Family

Empowerment; SOC = Sense of Coherence

Testing Assumptions for the Planned Analyses

Normality

One assumption of parametric statistical tests, such as linear and multiple linear

regressions, is that the continuous variables' distributions of scores roughly fit a bell-shaped

curve. As may be seen from the computed values for skewness and kurtosis in Table 3, there

were no meaningful indicators of marked deviations from normality from these indices, in

spite of statistically significant ($p < .001$) outcomes for the Shapiro-Wilk tests. Visual

inspection of histograms also showed some negative skew in all distributions. However, there were reasonable approximations of a normal distributions of data for all measures.

Assumptions of Bivariate Correlations

As each of the analyses for Research Questions 1 through 4 involved only one continuous predictor of one continuous dependent variable, the relevant assumptions of bivariate correlations apply. The assumptions that were evaluated were the following.

Linearity. This assumption presumes that if the two variables are related, it is in a linear, rather than curvilinear, nonlinear fashion. This assumption may be tested by examining patterns of data points in scatterplots of the paired values of the two variables. Scatterplots were created for the pairs of variables assessed in simple linear regressions for RQs 1 – 4. There were no indications of problems with nonlinearity.

Homoscedasticity. Homoscedasticity also was evaluated by examining the same scatterplots, but this time to see if the values on the two variables had similar variability, meaning that there was a spread of scores, from low to high, and pairs of values along both variables. Heteroscedacity would be suggested if the values on one of the two variables tended to be only in one part of the values on the other variable. There did not appear to be any major problems with this assumption.

Tests of Research Hypotheses

The research hypotheses for this study involved testing parental stress, empowerment, perception of support, and coping as predictors of QOL as an indicator of family adaptation. Research questions 1 to 4 involved bivariate correlations between each predictor and QOL. Bivariate (Pearson) correlations between each predictor and the QOL total mean are

presented in Table 4. Note that there were statistically significant correlations between all

predictors except parental stress with overall QOL.

Table 4

Bivariate Correlations Between Each Predictor and QOL Scores

| QOL Scores | Predictors | | | |
	QRS	CHIP	FES	SOC
Overall QOL	-.07	.42***	.43***	.47***
Physical Health	-.09	.38***	.32***	.44***
Psychological Health	-.04	.44***	.52***	.40***
Social Relationships	-.08	.43***	.38***	.47***
Environment	-.07	.28***	.33***	.40***

Note. QRS = Family Stress; CHIP = Coping; FES = Family Empowerment; SOC = Sense of Coherence; *** $p < .001$

Interpretation of Data

As simple bivariate correlations would indicate (See Table 4), scores for parental

stress (QRS) were not statistically significant predictors overall or type-specific forms of

QOL. A supplemental reverse multiple linear regression, with QRS score regressed on the

various QOL scores, mirrored this finding: $F(4, 256) = .721$, $p = .58$; $R^2_{adj.} = -.004$. Thus, the

null hypothesis for RQ1 could not be rejected.

As predicted, there were statistically significant bivariate relationships ($p < .001$)

between parental experience of empowerment (FES) and overall QOL ($r = .43$), as well as

QOL subscales, particularly psychological health ($r = .52$). Results from a multiple linear

regression with FES scores regressed on scores for QOL also indicated a significant overall

relationship: $F(4, 257) = 24.29$, $p < .001$; $R^2_{adj} = .263$. Relative relationships for each of the

dimensions of QOL, controlling for other dimensions of QOL, are shown in Table 5. FES

were significantly related to QOL, especially one dimension of QOL, psychological health, when controlling for other QOL scores. Thus, the null hypothesis was rejected for RQ2, with recognition that the relationship between family empowerment and QOL is primarily defined through relationships between empowerment and psychological health. I stopped reviewing here. Please go through the rest of your chapter and look for the patterns I pointed out to you. I will now look at Chapter 5.

Table 5

Coefficients of Prediction for Relationships of Family QOL Scores to Family Empowerment

| QOL Dimension | Unstandardized Coeff. | | Standardized | | |
	B	Std. Error	Beta	t	Sig.
Physical Health	-2.08	.154	-.120	-1.35	*n.s.*
Psychological Health	.829	.124	.584	6.70	<.001
Social Relationships	.055	.074	.070	.740	*n.s.*
Environment	-.057	.107	-.047	-.530	*n.s.*

Results from a multiple linear regression with SOC scores regressed on scores for QOL also indicated a significant overall relationship: $F(4, 255) = 21.49$, $p < .001$; $R^2_{adj} = .24$. Relative relationships for each of the dimensions of QOL, controlling for other dimensions of QOL, to SOC are shown in Table 6. While SOC scores clearly were related to QOL, the

strongest relationship between SOC and QOL, when controlling for other subscale scores, was the QOL Social Relationships dimension. In general, the null hypothesis was rejected for RQ3. Parental sense of coherence was significantly related to QOL, particularly to QOL Social Relationships.

Table 6

Coefficients of Prediction for Relationships of QOL Scores to Parental Sense of Coherence

	Unstandardized Coeff.		Standardized		
	B	Std. Error	Beta	*t*	Sig.
QOL Dimension					
Physical Health	.131	.179	.158	1.74	*n.s.*
Psychological Health	.015	.060	.022	.249	*n.s.*
Social Relationships	.123	.036	.332	3.43	.001
Environment	.016	.052	.028	.314	*n.s.*

Results from a multiple linear regression with CHIP scores regressed on scores for QOL also indicated a significant overall relationship: $F(4, 256) = 20.11$, $p < .001$; $R^2_{adj} = .227$. Relative relationships for each of the dimensions of QOL, controlling for other dimensions of QOL, are shown in Table 7. Results clearly offered more indication that the statistically significant relationship between CHIP Scores and those for QOL were primarily

accounted for by statistically significant relationships between CHIP scores and those for

Psychological Health, Social Relationships, and Environmental dimensions of QOL, when

controlling for other QOL subscale scores. Thus, the null hypothesis was rejected for RQ 4.

Table 7

Coefficients of Prediction for Relationships of QOL Scores to Parental Coping

	Unstandardized Coeff.		Standardized		
	B	Std. Error	Beta	*t*	Sig.
QOL Dimension					
Physical Health	.104	.089	.106	1.17	*n.s.*
Psychological Health	.254	.071	.316	3.57	<.001
Social Relationships	.132	.043	.302	3.08	.002
Environment	.172	.062	.252	2.78	.006

A general entry linear regression was employed to evaluate RQ5 for the overall

measure of QOL. As might be expected from the bivariate correlations, the prediction model,

when all predictors were considered, was statistically significant, $F(4, 254) = 32.43$, $p < .001$,

accounted for 33.8% ($R = .58$) of the variance in overall QOL, and all but QRS contributed

significantly to the prediction of QOL. Table 6 presents the regression coefficients.

Table 8

Coefficients for Predictors of Overall QOL from General Linear Regression Analysis

| Predictor | Unstandardized Coeff. | | Standardized | | | 95% CI for B | |
	B	Std. Error	Beta	*t*	Sig.	Lower	Upper
QRS	0.22	0.41	0.03	0.53	*n.s.*	-0.58	1.02
CHIP	0.21	0.09	0.17	2.26	.024	-0.03	0.39
FES	0.16	0.05	0.23	3.33	.001	0.06	0.25
SOC	0.52	0.07	0.37	6.86	<.001	0.37	0.67

Note. QRS = Family Stress; CHIP = Coping; FES = Family Empowerment; SOC = Sense of Coherence

Secondary analyses of the four predictors for each subdimension of QOL are summarized in Table 7. The null hypothesis was rejected. Again, overall, with the exception of QRS for parental stress, there was substantial support of the general model as a predictor of subdimensions of QOL.

Table 9

Results of Multiple Linear Regressions for Perceived Stress (QRS), Family Empowerment

(FES), Sense of Coherence (SOC), and Coping (CHIP) As Predictors of Each Subdimension

of QOL

QOL Dimension	Predictor	Adj. R^2	Overall F^1	Sig.	Beta	t	Sig.
Physical Health	Full Model	.540	22.96^1	<.001			
	QRS				.028	.470	*n.s.*
	CHIP				.209	2.68	.008
	FES				.094	1.30	*n.s.*
	SOC				.364	6.45	<.001
	QRS				.050	.890	*n.s.*
	CHIP				.145	1.97	.049
	SOC				.268	5.06	<.001
Social Relations	Full Model	.319	31.18^3	<.001			
	QRS				.044	.780	*n.s.*
	CHIP				.260	3.49	.001
	FES				.117	1.69	-.093
	SOC				.375	6.96	<.004
Environmental	Full Model	.204	17.55^4	<.001			
	QRS				-.014	-.220	*n.s.*
	CHIP				.026	.320	*n.s.*
	FES				.227	3.02	.003
	SOC				.334	5.74	<.001

Note. QRS = Family Stress; CHIP = Coping; FES = Family Empowerment; SOC = Sense of Coherence [1] df = 4, 254

Summary

Overall, with the exception of QRS for parental stress, there was substantial support

of the general Double ABCx model of adaptation for parents with children with disabilities,

when applied to parents of children with ADCC. The following, and final, chapter will

discuss the study, conclusions, and recommendations for future studies.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

In this chapter, I will discuss this study's overall results, conclusions, and recommendations for future studies involving parents with children who have ADCC. The purpose of this study was to examine experiences of stress, resources, sense of coherence, and coping strategies as predictors of QOL among parents with children who have ADCC. The research questions were guided by application of the double ABCx model of family adaptation. I found that this model was useful for identifying and understanding adaptation processes among parents of children with ADCC.

Support for the ABCx Model

The double ABCx model of family crisis and adaptation (Lavee et al., 1985) was the theoretical framework for this study. In this framework, families are dealing with stressors, such as a disabled child. The double ABCx model (McCubbin & Patterson, 1983, 2008) incorporates coping and sense of coherence as elements in predicting positive adaptation. The double ABCx model includes categories of mediators between the external stressor (the child with the disability) the family's level of adaptation including amount of stress experienced by the parents (aA), parents' perceptions of available resources (bB), parents' appraisals of their ability to function as an effective family (cC), and the parents' styles of coping (BC). Factors A through C are mediators between the stressor and family adaptation, measured by how the parents perceive their quality of life.

Children with ASD and ADCC have many things in common. For example, the disabilities are not always readily visible, so their parents do not always receive acknowledgement or support for their positions or needs. ASD is one of the most inhibiting

disorders for a family to experience (Pozo et al., 2011). ASD usually involves several regions of the brain (Hall & Graff, 2012) while ADCC involves the corpus callosum, but may present with other disabilities. The causes of ASD and ADCC are unknown, but both usually present with difficulties with social skills, difficulty with insight and genuine relationships, and inability to express emotions or empathize appropriately; performance and verbal IQs are usually different. These behaviors are what cause parents of children with ASD the most stress (Mount & Dillon, 2014) while there has not been research on what parents of children with ADCC experience.

Because of similarities between the symptoms of ASD and ADCC as neurological disorders, and the background research on application of the double ABCx model (see Figure 2), I examined whether similar factors also would predict adaptability of parents of children with ADCC.

Reactive Stress

Family stress (aA) in response to the child's disability is one factor in the double ABCx model. I found that reactive stress to the child's condition did not predict QOL for this sample. This may have been an artifact of my sampling. All of the participants were parents who already had reached out and become involved in a support network with other parents of children with ADCC. Thus, with no comparison groups of parents who are not part of such a support group or parents who do not have a child with this kind of disability, it is difficult to know if the sample was representative of the range of stress that is related to the disability that may be experienced by other parents of children with ADCC. Future research should include these kinds of comparison groups to make sure that there is adequate variability in stress.

Family Resources

Resources (bB) included in the double ABCx model was operationally defined in this study as related to family empowerment (Nachsen, 2005) and was measured by the FES (Koren et al., 1992), a measure that evaluates a parent's perceived control over resources for meeting the needs of the disabled child and adapting to the needs of a child with a disability. Weiss, MacMullin, and Lunsky (2015) found that empowerment was a mediator between the level of a child's behavior problems and experiences of distress among a sample of mothers of children with ASD. I also found a significant positive relationship between a parent's sense of how to access and use resources for the benefit of their child with ADCC and their self-reported quality of life, particularly that related to psychological health and environmental security and opportunities (as measured by WHOQOL). The psychological health subscale of the WHOQOL assesses self-reported self-esteem, positive and negative feelings, and cognitive skills. The environmental subscale focuses on perceived resources such as financial; freedom, physical safety, and security; accessibility and quality of health and social care; home environment; and opportunities to acquire new information and skills. These results provide further support for the importance of families of children with ADCC to have information and opportunities to be proactive in the care of their children.

Questions on the FES ask about the parent's perceptions on several dimensions, including confidence to identify and know how to take actions for the child's needs, whether the actions occur in the family, with the service system, through to contacting legislators and other policymakers. Resources and a belief that a person can use these to support his or her child to grow also are critical for family adaptation among parents of children with ADCC.

Sense of Coherence

Just as predicted by the double ABCx model and supported by previous research with families of children with ASD, how a family appraises and understands their child's and family situation also was a significant predictor family adaptation, here, all four subdimensions of QOL. Sense of coherence may be the most critical predictor of adaptation as it is a basic appraisal stage that would then affect beliefs, attitudes, and emotions related to self-efficacy, control, manageability, and underlying meaningfulness of the family's situation. It would be the lens through with the parent/family makes some basic existential assumptions with emotional meaningfulness about the why and stability of their situation (Antonovsky, 1987).

Super, Wagemakers, Picavet, Verkooijen, and Koelen (2016) discussed the importance of identifying ways to strengthen sense of coherence in health promotion activities. According to Super et al., one problem is that the underlying mechanisms are not clear. Super et al. proposed that reflection processes may be targets for support and that these are interdependent with empowerment. This is an opportunity for further research to support adaptation among parents of children with ADCC.

Coping Strategies

The coping strategies that parents use (BC) add another dimension to the double ABCx model. The CHIP was used to measure parental coping with their child's disability/health status. I found that ability to cope with ongoing changes and demands of parenting children with ADCC increases parents' positive perceptions of their QOL, in particular, physical health, psychological health, and social relations dimensions of QOL. Lai and Oei (2014) also found that positive coping, as measured by the CHIP, was associated

with increased social support, which also was related to less depression, anxiety, and anger outcomes. Thus, consistent with Folkman and Lazarus' (1986) theory of stress and coping, strategies that attempt to focus on the problem/task at hand and reach out for social support are more supportive of family adaptation than relying on emotional coping for families of children with ADCC. I stopped reviewing here. Please go through the rest of your chapter and look for the patterns I pointed out to you. I will now look at your references.

Limitations of the Study

There are limitations on the generalizability of the results of this study. First, all respondents were female. We have no information about fathers' experiences. Also, as discussed earlier, it is difficult to know if the volunteer participants were truly representative of the population of families of children with ADCC. Participants were drawn from those who already have been proactive in becoming involved in an online support and informational network. Are they the same as those who may be using other types of support, such as face-to-face and local? Are they the same as those who have not reached out for support or are in the very early stages of learning of their child's diagnosis? These unsampled groups may experience considerably higher stress, less of a sense of empowerment or coherence, and yet different coping methods than those in the support activities.

Unlike previous work with parents of children with ASD (for example, Hayes & Watson, 2012), there was no comparison group, such as parents of typically developing children. Thus, it is difficult to identify if there are factors or processes for family adaptation that may be unique to families of children with ADCC, relative to those with children with ASD or with typically developing children.

Recommendations

As this was the first examination of family adaptation among parent of children with ADCC, it only begins to try to tell their story. Both qualitative and quantitative studies may offer further understanding of their experiences and needs. This study only offered information on mothers of children with ADCC. We need additional research to sample fathers, as well as joint parent reports.

Conclusions and Social Implications

This study offers the first systematic exploration of adaptation among children with ADCC. Results support the application of the Double ABCx model for this group of parents. As such it is a step toward providing professionals some guidance into the conditions and processes that support families of children with ADCC. We are now tasked with asking, what might be the most effective ways to translate findings from research into the planning and provision of support for their needs through local or other resources? There is much more work to be done.

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Appendix A: Demographic Questionnaire

Are you over 18 years old?

Yes_____

No_____

Are you a parent of a child with a corpus callosum disorder (ADCC)?

Yes_____

No_____

Is your child with ADCC between the ages of 0-12 years?

Yes_____

No_____

Which country do you live in?_____

The assessments are on the internet (Facebook) and in English, do you want to proceed?

Yes_____Link to survey

No_____Thank you anyway.

I need more information (Link to email sent to Peggy Henninger, researcher)