Predictors of Mental Health in Parents of Children with Epilepsy

by

Jeffrey Carlson

A Thesis Presented in Partial Fulfillment
of the Requirements for the Degree
Master of Science

Approved April 2015 by the
Graduate Supervisory Committee:

Paul A. Miller, Chair
Perla Vargas
Nicole Roberts

ARIZONA STATE UNIVERSITY

May 2015

ABSTRACT

This study was designed to contribute to the existing research on the coping behaviors, social support, and mental health outcomes in parents of children with epilepsy in the United States. A questionnaire was disseminated and administered via a web-based interface. One hundred and fifty-two participants, predominantly Caucasian, married women with more than one child under the age of eighteen completed the survey.

After controlling for demographic variables, mediational analysis revealed that perceived social support explained the relation between perceived child disability and depression and anxiety. Additionally, it partially explained the relation between perceived family burden and depression, anxiety, and stress. Further, parent perception of their child's disability and perceived family burden did not predict emotion-focused or social support coping. However, both emotion-focused and social support coping behaviors were related to reductions in depression in this sample.

TABLE OF CONTENTS

Page

Page

APPENDIX

LIST OF TABLES

Table Page

LIST OF FIGURES

INTRODUCTION

Pediatric epilepsy, the most common neurological disorder in children, affects 1 in 200 (Rodenburg, et al., 2005) or approximately 326,000 between the ages of 0-17 in the United States (Buelow et al., 2006). Epilepsy is characterized as a central nervous system disorder in which nerve cells within the brain behave abnormally, causing seizures, potential loss of consciousness, and brain damage (Savage, 2014).

Children suffering from epilepsy face numerous challenges within educational, medical, and social domains and they deal with the emotional consequences of living with the condition. When compared to non-epileptic children, children living with epilepsy are more likely to suffer from internalized problems, such as affective or anxiety disorders (Caplan et al., 2005; Rodenburg et al., 2005b; Alfstad et al., 2011) and depression (Berg et al., 2011, Reilly et al., 2013), and attempted suicide (Caplan et al., 2005). They experience school-related problems, such as attention difficulties at higher rates than normal children (Austin et al., 2002; Davies, Heyman & Goodman, 2003; Rodenburg et al., 2005a), and high rates of learning disabilities (51%) (Cushner-Weinstien et al., 2008)

Internalized problems, however, are not the only challenges experienced by these children. Children with epilepsy have higher rates of external behavioral problems (i.e., aggression and refusal to follow rules) in comparison to both healthy children (Alfstad et al., 2011; Austin & Caplan, 2007; Austin et al., 2002) and children with other chronic illnesses (Rodenburg et al., 2005a). These findings suggest behavioral problems in children with epilepsy might be specific to the disorder, rather than a general characteristic of chronic conditions. Further, both internalizing and externalizing behavior potentially intensifies and increases negative interactions between parents and children thereby increasing the burden of parenting a child with epilepsy (Rodenburg et al., 2005b).

While the consequences of epilepsy on children's mental and behavioral health are well recognized (Rodenburg et al., 2005a), much less is known about its effect on primary caregivers. Internationally, the relation between parents' coping strategies and perceived social support in relation to their children's epilepsy have been directly related to mental health outcomes in Iran (Soltanifar et al., 2012), Taiwan (Mu, 2005; Mu, Kuo & Chang, 2005) and the Netherlands (Rodenburg et al., 2007). However, few studies have specifically assessed the role of parental coping strategies and perceived social support on negative mental health outcomes of caregivers for children with epilepsy in the United States.

Accordingly, the purpose of this study is to determine whether coping strategies and perceived social support mediate the relation between parents' perception of their child's disability/family burden and parent mental health outcomes (depression, stress, and anxiety).

Epilepsy

History. For the past 4000 years people have been aware of, and writing about, epilepsy (de Boer, 2010). Historically, however, doctors, philosophers, and healers held contrasting views regarding the causes and origin of the disorder, conceptualizing epileptic symptoms as demonic possession, divine intervention, and a waxing crescent moon heating the atmosphere, which melted the individual's brain and produced a seizure (de Boer, 2010).

It was not until the 18th century that medicine, grounded in scientific theory, began rebuking such theories in favor of physiological explanations for seizures (de Boer, 2010). Specifically, the work of British neurologist John Hughlings Jackson, commonly referred to as the father of modern epilepsy (Loring, 2010), produced a working definition of a seizure as “an occasional, sudden, excessive, rapid and local discharges of grey matter” within sensorimotor homunculi of the contralateral hemisphere (Akimoto, 2004, p 104). However, despite advances in modern brain imaging technology, such as CAT scan and MRI, and carefully crafted scientific experiments, explanations for the cause of epilepsy remain within the sacred, supernatural realm for some cultures. For instance, individuals in China attribute epilepsy to demonic possession (Kleinman et al., 1995) or insanity, as a result of being morally culpable for a negative behavior (Lim & Tam, 2014).

Definitions. Even with the above-mentioned advances, researchers and clinicians have continued to examine the distinction between a seizure and epilepsy, a distinction that has experienced numerous changes. Generally, seizures occur when the normal pattern of neuronal activity in the brain becomes disturbed, potentially producing convulsions, muscle spasms, and loss of consciousness (NIH, 2013). This definition experienced only minor revision since Jackson’s first definition. The characterization of epilepsy, however, was recently shifted from a disorder to a disease, citing the public’s poor understanding of the term disorder (Fisher et al., 2014). As such, the Internal League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), two prominent international organizations working to improve understanding of epilepsy, have recently redefined define it as:

1. At least two unprovoked seizures occurring >24 hours apart
2. One unprovoked seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over 10 years
3. Diagnosis of epilepsy syndrome (Fisher et al., 2014)

Etiology. Three main etiological classifications exist for epilepsy: genetic, structural/metabolic, and unknown (Berg et al., 2010). Genetically, epilepsy may result from defects, such as mutation of voltage-gated sodium and potassium channels, which produce abnormalities in function without gross neuroanatomical structure (Berkovic et al., 2006). This particular mechanism is most often attributed to epilepsy in children (Smith, 2012; Bhalla et al., 2011). Structurally/metabolically, epilepsy can occur from genetic or acquired factors, such as underdevelopment of cortical areas (genetic) or lesions from stroke, trauma, or infection (acquired) (Shorvon, 2011a). Unknown factors also exist, but current scientific methods have not yet found, and currently remain unable to find, a cause for these cases (Shorvon, 2011).

Further, children are especially at risk for seizures during periods of cortical development. The elevated prevalence of epilepsy may be the result of brain regions possessing excitatory GABAergic neurotransmitter receptors early in development; receptors that develop into inhibitory receptors later in adulthood (Elger & Schmidt, 2008). Consequently, high levels of excitatory activity in the brain may induce seizures and help to explain the high prevalence of the disorder in children (Elger & Schmidt, 2008).

Epidemiology. According to the World Health Organization (WHO), there are 50 new cases of epilepsy each year per 100,000 people worldwide with incidences as high as 239 per 100,000 in some rural areas of developing countries (Ngugi et al., 2011).

Additionally, epilepsy affects around 1 in 200 people globally, with higher prevalence rates in developing regions (WHO, 2014). Given the incident and prevalence rates, epilepsy remains a global concern.

Treatment. Considering the potentially debilitating effects of seizures on children, individuals suffering from epilepsy typically seek medical treatment to mitigate the disorder. Most frequently, the first line of treatment physicians employ is an antiepileptic drug (AED) (Appleton, 2012). AEDs have been shown to be up to 70% effective in reducing seizure frequency and severity (Elger & Schmidt, 2008). Currently, more than 20 AEDs are available on the market by prescription, each with varying side effects (Cross, Kluger & Lagae, 2013). Careful consideration of costs and benefits of each drug must be assessed by parents when seeking AED therapy (Cross, Kluger & Lagae, 2013). In the event a single AED is unsuccessful, a second AED is typically added to the treatment plan (Appleton, 1995).

If children remain unresponsive to combinations of AEDs, the child is said to have intractable epilepsy (inability to control the seizures through treatment) (Appleton, 1995). Intractable epilepsy may interfere with a child's quality of life, thus, in many of these cases, parents may opt to use alternative treatments such as the ketogenic diet (i.e., a high fat, carb-restricting diet) (Neal et al., 2008) or use cannabidiol, a non-psychoactive compound found in marijuana (Porter & Jacobson, 2013). As a last resort, some parents elect for their child to undergo surgical removal of brain regions associated with seizure foci (Elger & Schmidt, 2008).

Parenting a Child with Epilepsy

Given the options that parents face in the selection of treatments to reduce their child's epilepsy, and the likelihood of their child's adjustment problems (Caplan et al., 2005; Rodenburg et al., 2005b; Alfstad et al., 2011), parenting a child with epilepsy has been shown to negatively affect the mental health of caregivers (Rodenburg et al., 2007, Mu, 2005). As such, it is important to examine the factors associated with parenting a child with epilepsy that contribute to parents' mental health effects, namely stress, anxiety, and depression.

Stress. Parents of children with epilepsy report high levels of stress for various reasons. Buelow et al. (2006) conducted semi-structured interviews with twenty parents in an attempt to categorize the major sources of stress parents experience as a result of their child's epilepsy. The study identified five major sources of stress for parents:

1) Concerns about the child (future and transition issues, behavioral problems, consequences of seizures)
2) Communication with healthcare providers (medication problems, need for information, time to diagnosis)
3) Changes in family relationships (marital relationships, sibling relationships, leisure-time activities, support from extended family)
4) Interactions with school (communication, transition issues, child safety, socialization)
5) Support within the community (work issues and financial concerns, family counseling and respite care) (Buelow et al., 2006).

Such stress may also be the result of seizures associated with epilepsy being viewed by parents as a traumatic and unpredictable event (Iseri, Ozten & Aker, 2005). Consequently, the sudden onset and inability to control seizures when they occur leaves parents feeling vulnerable, thereby increasing their stress levels (Cushner-Weinstein et al., 2008). Further, experiencing an individual having a seizure can be a frightening and traumatic incident, producing thoughts of uncertainty regarding potential health implications for the child (Mu, 2005).

Additionally, approximately half of children with epilepsy also elicited behavioral problems that contributed to parental stress (Reilly et al., 2013; Austin, Risinger, & Beckett, 1992), In a 2007 study, Rodenburg et al. (2007) measured parent-reported child behavioral problems including aggression, that resulted from epilepsy. In parents, they found that the level of stress and relationship dissatisfaction with their child correspondingly increased with the frequency of their child's behavioral problems.

In addition to characterizing the stressful nature of parenting a child with epilepsy, Cushner-Weinstien et al. (2008) studied the prevalence of stress in parents of children with epilepsy. They found that 45% of parents reported high levels of stress as a result of their child's epilepsy-induced learning disabilities and depression. These results are similar to the reports of parents of children with varying disabilities such as traumatic brain injury (Hawley et al., 2003) and spina bifida (Vermaes et al., 2005).

Beyond parental stress associated with their child's cognitive/behavioral problems and consequences of their seizures, epilepsy-related social stigma likely interferes with interactions at school and in the community, subsequently producing an additional source of parental stress. Carlton-Ford et al. (1997) asked parents to self-report the level of seizure severity and perceived social stigma surrounding the disorder. They found a positive association between self-reported seizure severity and perceived stigma. That is, parents were concerned with the opinions of others when their child developed a seizure outside the home setting and, consequently, experienced high levels of stress when they occurred. Similarly, and in support of these findings cross-culturally, Ju et al. (1990)

found 80% of Chinese parents attempted to conceal their child’s epilepsy for fear of social discrimination. Such concealment, Ju et al. (1990) concluded, decreased their utilization of potential support systems and was attributed to increases in stress.

These findings are significant because high levels of stress in parents have been associated to negative mental health outcomes such as depression (Iseri, Ozten & Aker, 2005) and anxiety (Soltanifar et al., 2012). As such, the relation between parenting a child with epilepsy and depression and anxiety will be explored in greater detail.

Depression and Anxiety. Parents who experience higher levels of stress when caring for their epileptic children also may be at an increased risk for depression. In the United States, depression is estimated to occur in 46% of parents with an epileptic child (Wood et al., 2008) and may be associated with increases in their child’s epilepsy-induced behavioral problems (Shore et al., 2004; Shore et al., 2002).

The effect of epilepsy on parental depression varies across cultures. In Turkey, Baki et al. (2004) found no difference in rate of depression between parents of children with epilepsy and the general population. However, mothers of children with epilepsy from countries such as Iran (Soltanifar et al., 2012), the Netherlands (Rodenburg et al., 2007), Taiwan (Mu, 2005; Mu, Kuo & Chang, 2005), and China (Chiou & Hsieh, 2008; Lv et al., 2009) display high levels of depression. Similar to studies in the United States (Shore et al., 2004; Shore et al., 2002), rates of depression in the Netherlands were partially related to the demands of parenting a child with increased epilepsy-induced behavioral problems (Rodenburg et al., 2007).

It is important to understand the rates and causes of depression in parents in any culture when considering the potential impact on the child. Chiou and Hsieh (2008) found that parental depression was associated with poor adaptability (poor self-esteem, social withdrawal and behavior) in children with epilepsy compared to children with asthma. In addition, parental anxiety is related to negative effects on their child's adaptive functioning (Chapieski et al., 2005; Kerne & Chapieski, 2015) and quality of life (Williams et al., 2003; Li et al., 2008; Lv et al., 2009) in the child with epilepsy.

These results suggest that the effect of parenting a child with epilepsy on parental depression and anxiety may occur cross-culturally. Given the high rates of negative mental health outcomes in this population, this research suggests that it would be important to explore additional factors, such as coping strategies and perceived social support that may reduce or contribute to the effects of parental depression, stress, and anxiety in parents of children with epilepsy.

Coping Strategies. Despite growing evidence that caring for a child with epilepsy has implications for caregivers' level of stress and mental health outcomes, much less is known about how caregivers in this situation cope with such stress. One model developed to study stress is the transactional model proposed by Lazarus and Folkman (1984). This model suggests that situations are considered stressful when an individual evaluates a stressor as potentially harmful or threatening and further determines that they lack the resources necessary to overcome the threat. In this model, coping represents the "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus and Folkman, 1984, p. 141).

Utilizing this definition, parents may employ specific cognitive and behavioral strategies to minimize the external and internal demands of caring for a child with epilepsy. Lazarus and Folkman's model (1984) suggests two main coping strategies, problem-focused and emotion-focused coping. Problem-focused coping, they propose, is utilized when an individual appraises the situation as modifiable, whereas emotion-focused coping is used when the individual perceives the stressor as unchangeable, and in the case of this study, does not include seeking social support.

Coping behaviors of parents of children with epilepsy have been studied internationally. In the Netherlands, parents of children with epilepsy employing emotion-focused coping behaviors had lower mental health scores than those using problem-focused coping behaviors (van Andel et al., 2011). Additionally, the use of emotion-focused coping strategies (i.e., "Searching for cheerful company if you are worried or upset") when caring for a child with epilepsy was related with higher levels of stress, whereas the use of problem-focused coping (i.e., "Directly interfering in the event of difficulties") was related to reductions in stress and depression (Rodenburg et al., 2007). In addition to the Netherlands, similar effects of parenting coping strategies were observed in Asia (Mu, 2005).

In Taiwan, researchers assessed the strategies mothers (Mu, Kuo & Chang, 2005) and fathers (Mu, 2005) used to cope while caring for a child with epilepsy utilizing the Coping Health Inventory for Parents. This measure of coping has three subscales: 1) maintaining family integration, cooperation, and optimistic view of the situation, 2) maintaining social support, self-esteem and psychological stability and, 3) understanding the medical situation through communication with other parents and consultation with medical staff. Mothers used coping strategy one with the greatest frequency, however, both the first and third coping strategies resulted in reductions in self-reported levels of depression (Mu, Kuo & Chang, 2005). Similar to mothers, fathers who utilized the first and third coping strategies produced lower levels of depression (Mu, 2005). Conversely, in fathers, the use of coping strategy two, emotion-focused coping, produced increases in the level of self-reported depression. In summary, problem focused or active coping strategies seem to buffer the effects of caregiving on the stress and depression in both fathers and mothers. However, in mothers it remained unclear whether emotion-focused coping behaviors affected mental health outcomes. Further, in the United States the effects of coping behaviors on the relation between perceived child disability and family burden and mental health outcomes in parents of children with epilepsy remains unstudied.

Social Support. There are a number of approaches to operationalizing social support. Jones and Bright (2001) suggest that social support can be defined as the resources available to an individual (perceived) or offered (received) by others as well as a coping strategy in which a person actually seeks or uses social support to deal with a stressor. The perception of (Falk, Norris & Quinn, 2014), and reception of (Smith, Greenburg & Seltzer, 2012) social support, in addition to its use as a coping strategy (Boyd, 2002), is known to reduce the rate of depression, anxiety, and stress in mothers of children with other chronic conditions such as autism. In mothers of children with epilepsy, nearly 30% report feeling inadequately supported and overburdened by their child's disease, 40% feel socially isolated from relatives, peers and emotional support, and over 50% feel insufficient support from their spouse (Wirrell et al., 2008). To date, however, few studies in the United States have addressed the role of social support in mitigating mental health outcomes in parents of children with epilepsy. Shore et al.,

(2002) provides one such study, finding greater use of social support reduced depressive symptoms in parents.

However, the use or reception of social support may not be necessary for the minimization of negative mental health outcomes in parents. In the Netherlands, Rodenburg et al. (2007) suggests the perception of available social support can reduce depressive symptomatology and stress in parents of children with epilepsy. As evidenced by the limited research on the effect of social support on parenting a child with epilepsy, it remains unclear whether parental perceived social support or actual social support seeking by parents affects their mental health outcomes.

Cross-cultural Differences in Coping Strategies and Social Support

Many studies that assessed the effects of caring for a child with epilepsy on parents have been conducted outside of the United States (Rodenburg et al., 2007; Mu, Kuo & Chang, 2005; Chiou & Hsieh, 2008; Lv et al., 2009). However, Patterson et al., (1998) evaluated the differences in coping behaviors between Chinese and American caregivers of individuals with Alzheimer's disease. They found that Chinese caregivers used more problem-focused coping behaviors than American caregivers. This study offers insight into potential ethnic and cultural differences in coping strategies.

To address the role of cultural variability on coping, Knight and Sayegh (2009) reviewed studies on cultural variability in coping styles and proposed a model that builds on Lazarus and Folkman's (1984) transactional model of stress and coping. They propose coping style and social support are shaped by, and contingent upon, the cultural and ethnic values of the individual (Knight & Sayegh, 2009).

For example, the effect of culture on coping strategies and mental health outcomes may be influenced by the collectivist or interdependent nature of society in East Asia (Chun, 2004). Specifically, Chun (2004) argues individuals from Asian countries may be more likely to use social support and problem-focused coping as a result of their interconnected communal view of society. Conversely, however, Taylor et al. (2004) found that both Asian and Asian American individuals sought out less emotional and instrumental social support than European Americans when thinking about a recent stressful experience. Further, European Americans were significantly more likely to use active coping strategies, a component of problem-focused coping, for dealing with stressors than Asian and Asian Americans (Taylor et al., 2004).

Studies addressing the coping behaviors in parents of children with epilepsy have mainly occurred outside of the United States. Further, given the differences in coping behaviors across cultures, as evidenced in these findings, the exploration of perceived social support and coping strategies utilized by American parents of children with epilepsy living in the United States is warranted.

Current Aims

This thesis aims to contribute to the research on factors that impact the mental health outcomes of parents of children with epilepsy within the United States. Specifically, the purpose of this study is to examine the relation between parents' perceived child disability and family burden on parental mental health outcomes (depression, anxiety, and stress). Additionally, it seeks to explore whether perceived social support and coping strategies mediates, or can partially or fully explain, the observed relation between perceived child disability and family burden on parental mental health outcomes.

Hypothesis 1: Based on previous findings (Rodenburg et al., 2007), emotion-focused coping will mediate the association between parental perceived child disability and mental health outcomes such that increased use of emotion-focused coping will result in higher levels of depression, anxiety, and stress.

Hypothesis 2: Parental social support seeking, as a coping behavior, will mediate the relation between perceived child disability and mental health outcomes such that use will reduce depression, anxiety, and stress (Taylor et al., 2004; Shore et al., 2002).

Hypothesis 3: Parental perceived social support will mediate the relation between perceived child disability and mental health outcomes, such that decreasing perception of social support will increase their levels of depression, anxiety, and stress (Rodenburg et al., 2007)

Hypothesis 4: Emotion-focused coping will mediate the association between parental perceived family burden and mental health outcomes such that increased use of emotion-focused coping will result in higher levels of depression, anxiety, and stress (van Andel et al., 2001).

Hypothesis 5: Social support seeking, as a coping behavior, will mediate the relation between family burden and mental health outcomes such that social support use will reduce their depression, anxiety, and stress

Hypothesis 6: Perceived social support will mediate the relation between family burden and mental health outcomes, such that decreasing perception will increase their levels of depression, anxiety, and stress

METHOD

Participants

Approval from the Institutional Review Board at Arizona State University was obtained. Participants were recruited online through Facebook discussion boards and groups as well as various discussion forum websites related to parenting a child with epilepsy including: epilepsy.com, healthboards.com/epilepsy, epilepsyfoundation.com, healingwell.com, and coping-with-epilepsy.com.

Based on previous studies (van Andel et al., 2011; Mu, 2005; Mu, Kuo & Chang, 2005), criteria for eligibility included parenting a child between the ages of 0 and 18, who was diagnosed with epilepsy. All participants were directed to surveymonkey.com, via a link provided in the post, where the questionnaires were administered. Participants' consent was obtained on the first page of the survey, and continuation was contingent upon the participant selecting yes to the statement, "Do you agree to the above terms? By selecting 'Yes' you are giving consent that you are willing to answer the questions in this study." Participants were allowed to withdraw from the study at any time and notified that their participation was completely voluntary. Aside from the demographic survey, all questionnaires were administered in a randomized order determined by Survey Monkey. Additionally, all questionnaires are parent self-reported and will be referred to as parent when referring to the variables to limit repetitive use.

Responses from 329 parents of children with epilepsy were collected. Among these, 177 were filled to less than 15%. As a result, a final sample of 152 participants met the inclusion criteria, of which 145 were female (95.4%) and 4 were male (2.6%), 3 were missing sex information (2%); the mean age was 39.5 years old (SD = 7.51, range = 21-56), and the average number of children per family was 2.65 (SD = 1.43, range = 0-11).

Measures

Mediators.

Coping strategies. Participants completed the full COPE inventory developed by Carver, Scheier, and Weintraub (1989). The questionnaire is composed of 15 subscales, with each subscale consisting of 4 items measuring a specific type of coping strategy for a total of 60 questions. The scales are: Positive reinterpretation, mental disengagement, venting of emotions, instrumental social support, active coping, denial, religious coping, humor, behavioral disengagement, restraint, emotional social support, substance use, acceptance, suppression, and planning. Participants reported on a four-point Likert scale ranging from 1 to 4 (1 = “I usually don’t do this at all”, 4 = “I usually do this a lot”) to indicate the degree to which they usually engage in the behavior or feeling when experiencing stressful events. Higher scores indicate greater use of coping strategy.

Carver, Scheier, and Weintraub have argued Lazarus’s categorization of coping into problem and emotion-focused is too broad (Jones & Bright, 2001). However, in order to compare results with previous studies on parenting children with epilepsy, subscales were grouped into three larger coping scales similar to Lazarus, as outlined by Fisher, Segal and Coolidge (2003). The three coping scales proposed by Fisher, Segal and Coolidge (2003) were as follows: Emotion-focused strategies (acceptance, humor, positive reinterpretation, religious coping), problem-focused (active coping, planning, restraint, suppression) and dysfunctional strategies (behavioral disengagement, denial, suppression, substance use, venting of emotions). In addition, it should be noted that instrumental and emotional social support subscales were combined to form an overall measure of social support seeking (Taylor et al., 2004). Both emotion-focused and social support coping displayed acceptable internal reliability in the current study, Cronbach's αs of .76 and .87 respectively.

Perceived social support. The Interpersonal Support Evaluation List (ISEL), a 40-item instrument, was used to assess participants' perceived accessibility of possible social resources (Cohen & Hoberman, 1983). Participants reported on a four-point Likert scale ranging from 0 to 3 (0 = "definitely false", 3 = "definitely true"). The ISEL is composed of four social support subscales, ten questions each, measuring; tangible (perceived availability of palpable aid), appraisal (perceived availability of emotional support), self-esteem (perceived availability of someone else to positively compare oneself with), and belonging (perceived availability of people to engage socially with) components. Higher scores indicate greater perceived social support.

Heitzmann and Kaplan (1988) demonstrated and supported its validity and reliability finding a test-retest coefficient of .87 and high correlation with other measures of social support. Further, the perceived social support of caregivers for individuals who had a stroke was found to negatively correlate with depression, when measured with the ISEL (Grant et al., 2001). In the current study, the scale had a high level of internal consistency, as determined by a Cronbach's alpha of .96.

Predictor variables.

Parental perception of child with epilepsy. Parents' perceptions of the impact of the perception of their child's disability on their stress were measured using the 52-item Questionnaire on Resources and Stress Friedrich Edition (QRS-F) (Friedrich, Greenberg

& Crnic, 1983). The measure consists of four subscales: child characteristics (features of the child that increase the demand on the parent, e.g. “doesn't do as much as he/she should be able to do”), child incapacitation (the range of activities a child cannot perform, e.g. “cannot remember what he/she says from one moment to the next”), parent and family problems (impact of the child’s disability on parents and other family members, e.g., “Other members of the family have to do without things because of ______”), and pessimism (pessimistic view of the child’s future, e.g. “I often worry about what will happen to _______ when I can no longer care for him/her”). The scale utilizes dichotomous true/false responses (True = 1, False = 0) to assess components of parental perception. Child characteristics and child incapacitation were combined to form a child disability measure (Honey, Hastings, & McConache, 2005). Higher scores indicate greater perceived severity of disability. Later use of child disability will refer to severity of the disability. In this study, this scale also revealed a high internal reliability, Cronbach’s $\alpha = .98$.

Family Burden. Parents’ perception of the degree to which their child’s epilepsy causes strains on the family was measured with the Impact on Family Scale (IOFS) (Stein & Riessman, 1980). The survey consists of 27 statements subdivided into four dimensions. The four dimensions include: financial (the degree to which the child’s illness affects the family economically), familial/social (the degree to which the child’s illness affects communication within and outside of the family), personal strain (parental experienced strain resulting directly from the child’s illness), and mastery (coping strategies utilized by the parent to reduce the illness induced stress). A Likert scale ranging from 1 to 4 (1 = “strongly disagree”, 5 = “strongly agree”) was used to assess participants' agreement with each statement. Items were summed to produce a sub-score total, with higher values indicating greater burden (expect for mastery in which higher scores denote lower burden). The sub-scores financial, family/social, and mastery were combined to produce a composite measure of family burden. Strain was removed because the questions were too similar to the stress outcome variable used in this study. In the current study, the scale had a high level of internal consistency, as determined by a Cronbach's alpha of .96.

Outcome variables.

Depression, anxiety, and stress. Participants completed the Depression Anxiety Stress Scale (DASS) developed by P.F. Lovibond and Lovibond (1995). The questionnaire features 42 statements broken down into three subscales: depression (e.g. "I felt that I had nothing to look forward to"), anxiety (e.g. "I found myself in situations that made me so anxious I was most relieved when they ended"), and stress (e.g. "I found myself getting upset rather easily"). Participants reported on a four-point Likert scale ranging from 0 to 3 (0 = "Did not apply to me at all", 3 = "Applied to me very much, or most of the time") to indicate the degree to which each statement applied to them over the past week. Scores for each item in the three subscales are summed to produce a total score, which can then be compared to the scoring template to indicate the severity of each sub-score. A situational, rather than trait measure was utilized because it allowed for the study to capture the participant's response to the distress of parenting a child with epilepsy rather than dispositional personality characteristics, such as negative affectivity (Spielberger, 1983).

Although the Beck Depression Inventory (BDI) and the Beck Anxiety Inventory (BAI) have previously been used to assess mental health outcomes in parents of children with epilepsy (Mu, Kuo & Chang, 2005; Hosseini et al., 2010), the DASS was selected because of its inclusion of a stress scale and high correlations with both the BDI (r = 0.74) and BAI (r = 0.81) (Lovibond, P.F. & Lovibond, 1995). Including stress as a measure allows the DASS to further differentiate depression from anxiety, compared to the BDI and BAI. Scales were initially developed using clinical consensus definitions for each subscale. Subsequently, P.F. Lovibond and Lovibond (1995) used a factor analysis to empirically confirm the categories. They were able to include a stress subscale into the DASS by placing items not strongly correlated with depression from the BDI into the stress subscale. Cronbach's alphas for depression, anxiety, and stress were .94, .91, and .93, respectively.

Procedure

This cross-sectional study utilized web-based self-report questionnaires to explore the mediational effect of self-reported coping behaviors and perceived social support on the relation between perceived child disability and family burden and mental health outcomes in parents of children with epilepsy in the United States.

RESULTS

Descriptive Statistics

Descriptive statistics of participants' demographic variables are presented in Table 1. The majority of participants were Caucasian (89.5%), married (78.9%), females (95.4%), with more than one child under the age of 18 (73%). In this sample, level of income was inversely related to depression, $r = -.29$, $p < .001$, anxiety $r = -.35$, p < .001, and stress, $r = -.22$, $p < .006$ as was education, $r = -.16$, $p = .05$, $r = -.22$, $p = .005$, $r = -.18$, $p = .031$ respectively. As such, level of income and education were statistically controlled for in the mediational analyses.

Table 1. Descriptive Statistics of Demographic Variables

Participant (Parent)	Response	*N* (%)
Age (Years)	*M* (*SD*)	39.53 (7.51)^a
Sex	Female	145 (95.4)
	Male	4 (2.6)
Ethnicity	White/Caucasian	136 (89.5)
	Hispanic American	8 (5.3)
	Latino	2 (1.3)
	African American	2 (1.3)
	Asian American	2 (1.3)
	Native American or Alaskan Native	2 (1.3)
Marital Status	Single	12 (7.9)
	Married	120 (78.9)
	Divorced	16 (10.5)
	Separated	1 (.7)
	Widowed	1 (.7)
Employment	Full-time	59 (38.8)

	Part-time	27 (17.8)
	Homemaker	56 (36.8)
	Student	5 (3.3)
	Retired	1 (.7)
	Disabled/unable to work	3 (2.0)
Income	Under $20,000	14 (9.2)
	$20,000-29,999	11 (7.2)
	$30,000-39,999	11 (7.2)
	$40,000-49,999	10 (6.6)
	$50,000-59,999	17 (11.2)
	$60,000-69,999	8 (5.3)
	$70,000-79,999	9 (5.9)
	$80,000-89,999	9 (5.9)
	$90,000-99,999	7 (4.6)
	Over $100,000	41 (27)
Highest Level of Education	K – 8th	1 (.7)
	Some high school, no diploma	2 (1.3)
	High school graduate or GED	13 (8.6)
	Some college, no degree	34 (22.4)
	Associates degree	17 (11.2)
	Bachelors degree	51 (33.6)
	Masters degree	23 (15.1)
	Professional degree	6 (3.9)
	Doctorate degree	4 (2.6)
Children Under 18	Yes	111 (73)
	No	41 (27)
Number of Children Under 18	*M* (*SD*)	2.65 (1.43)

Note. [a]*N*(%), values indicate the number of individuals followed by the respective percentage in parenthesis.

Table 2. Summary of Intercorrelations, Means, and Standard Deviations for scores on the predictors, mediators, outcome variables

Measure	M (SD)	1	2	3	4	5	6	7	8
1. Perceived Disability	.36 (.28)		.48*	-.04	-.31	-.45*	.47*	.42*	.20
2. Perceived Burden	2.39 (.53)			-.14	-.21	-.49*	.48*	.32*	.48*
3. Emotion-Focused Coping	2.60 (.47)				.25*	.24*	-.18*	-.03	-.12
4. Social Support Coping	2.85 (.67)					.29*	-.24*	-.02	-.08
5. Perceived Social Support	1.98 (.57)						-.36*	-.29*	-.43*
6. Depression	.56 (.58)							.68*	.69*
7. Anxiety	.49 (.56)								.71*
8. Stress	1.0 (.68)								

Note. Values indicate intercorrelations *$p < .05$

Direct Effect of Child Disability on Mental Health Outcomes

Parents' ratings of the perceptions of their children's disability were significantly related to depression, $b = .47$, $SE = .17$, $t = 2.84$, $p = .005$, and anxiety, $b = .42$, $SE = .16$, $t = 2.65$, $p = .009$, but not stress, $b = .20$, $SE = .23$, $t = 1.01$, $p = .32$, when controlling for level of income and education.

Relation Between Child Disability and Mental Health Outcomes with Emotion-Focused Coping as a Mediator

The relation between perceived child disability and emotion-focused coping was not significant, $b = -.04$, $SE = .15$, $t = -.30$, $p = .77$. Consequently, conditions for mediational analysis were not met. Thus, parents' use of emotion-focused coping could not be examined as a mediator of the relation between perceived child disability and parental mental health outcomes.

Relation Between Child Disability and Mental Health Outcomes with Social Support Coping as a Mediator

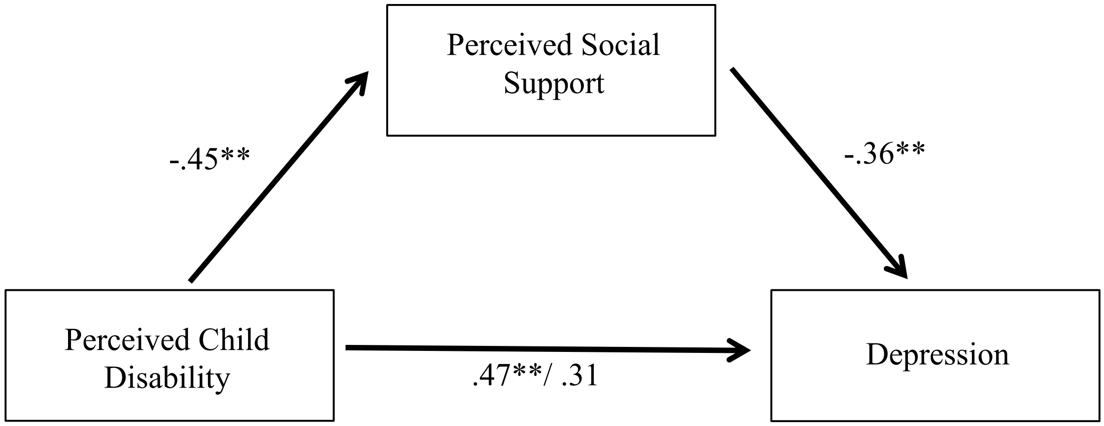
The relation between child disability and social support seeking were not significant, $b = -.31$, $SE = .21$, $t = -1.50$, $p = .14$. Therefore conditions for mediational analysis were not met. Accordingly, parents' use of social support coping could not be tested as a mediator of the relation between perceived child disability and parental mental health outcomes.

Relation Between Child Disability and Mental Health Outcomes with Perceived Social Support as a Mediator

Two regressions analyses were run to establish the necessary conditions for mediation. The first analysis tested the relation between parents' rating of the degree of child disability and perceived social support. This effect was significant, $b = -.45$, $SE = .15$, $t = -2.95$, $p < .01$. The second analysis tested the relation between perceived social support and depression, anxiety, and stress. These effects were all significant, $b = -.36$, $SE = .09$, $t = -4.16$, $p < .001$, $b = -.29$, $SE = .08$, $t = -3.53$, $p < .001$, and, $b = -.43$, $SE = .11$, $t = -4.11$, $p < .001$, respectively.

Three mediational analyses were performed to investigate if parents' perceived social support mediated the relation between perceived child disability and negative mental health outcomes when controlling for income and level of education. Bootstrapping analysis was used to estimate confidence intervals of the indirect effect, at the 95% level, enabling the determination of significant mediation.

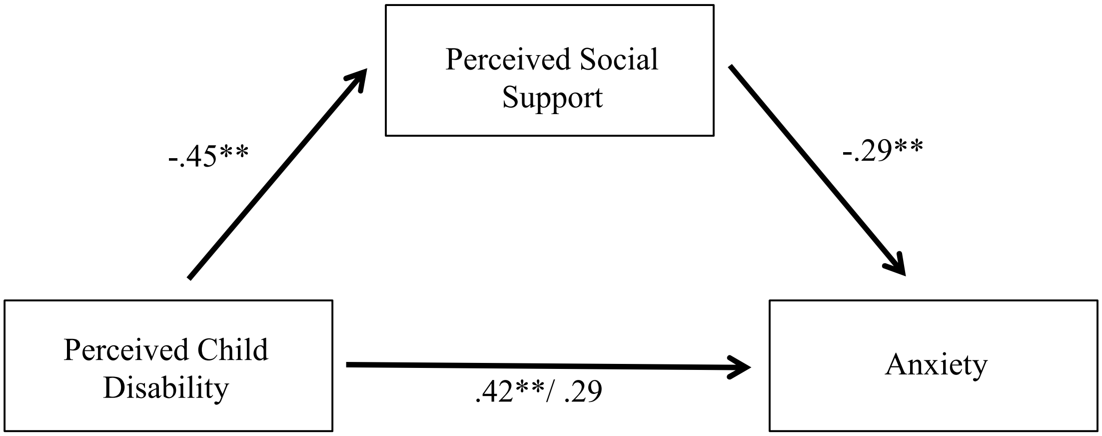
The first mediation analysis tested whether the effect of parents' ratings of the degree of child disability on parental depression would be mediated by parents' perceived social support when controlling for income and level of education. A bootstrapping procedure with 5000 samples was used to estimate the standard error and confidence intervals of the indirect effect (Hayes & Scharkow, 2013). Statistical analysis confirmed that parents' perception of the degree of social support available mediated the relation between their ratings of their child's disability and their self-reported depression, *b* = .16, *SE* = .07, *CI* = .05, .33, (Figure 1).



Note: Values indicate standardized regression coefficients (*$p < .05$, **$p < .01$)

Figure 1. Standardized regression coefficients for the relation between perceived child disability and parental depression as mediated by perceived social support.

The second mediation analysis revealed confidence intervals that did not contain zero (*CI* = .04, .28), indicating that parents' perception of the degree of perceived social support available significantly mediated the relation between their ratings of their child's disability and their self-reported anxiety (Figure 2).



Note: Values indicate standardized regression coefficients (**p* < .05, ***p* < .01)

Figure 2. Standardized regression coefficients for the relation between perceived child disability and parental anxiety as mediated by perceived social support

The third mediation analysis tested whether the effect of child disability on stress would be mediated by perceived social support. When controlling for income and level of education, the initial direct effect between parents' ratings of their child's disability and stress was not statistically significant, $b = .20$, $SE = .20$, $t = 1.00$, $p = .32$. Therefore conditions for mediation were not met.

Direct Effect of Family Burden on Mental Health Outcomes

Initial direct effects for perceived family burden on depression, $b = .46$, $SE = .08$, $t = 5.59$, $p < .001$, anxiety, $b = .32$, $SE = .08$, $t = 4.36$, $p < .001$, and stress, $b = .48$, $SE = .10$, $t = 4.78$, $p < .001$, were significant when controlling for level of income and education.

Relation Between Family Burden and Mental Health Outcomes with Emotion-Focused Coping as a Mediator

The direct relation between family burden and emotion-focused coping was not significant, *b* = -.14, *SE* = .09, *t* = -1.60, *p* = .11. Consequently, the relation between parents' perceptions of disease related family burden on mental health outcomes with emotion-focused coping as a mediator could not be executed.

Relation Between Family Burden and Mental Health Outcomes with Social Support Coping as a Mediator

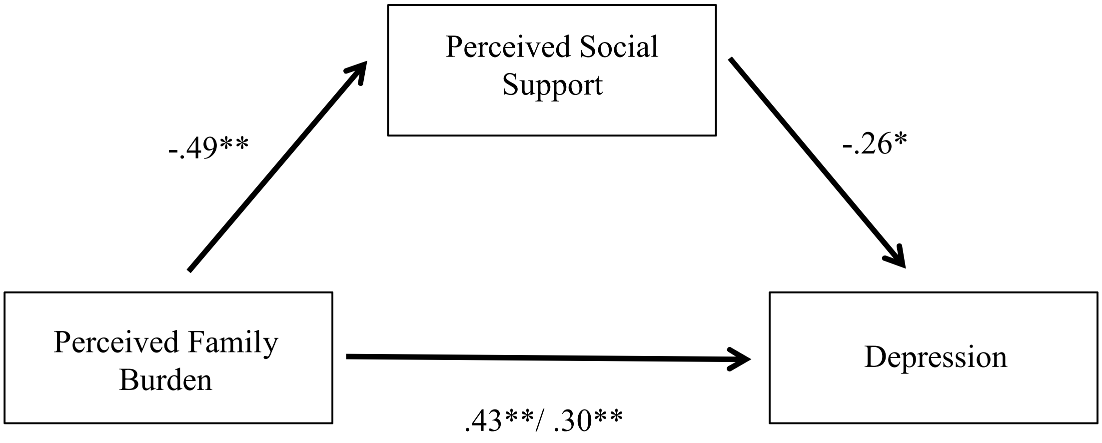
The direct relation between family burden and social support coping was not significant, *b* = -.21, *SE* = .11, *t* = -1.93, *p* = .06. Therefore, the role of social support coping as a mediator of the relation between perceptions of the burden of the disability on the family on mental health outcomes could not be conducted.

Correlation Between Family Burden and Mental Health Outcomes with Perceived Social Support as a Mediator

Two conditions were met to establish the necessary conditions for mediation. First, a regression was used to test the relations between perceived family burden and perceived social support. This relation was found to be statistically significant, *b* = -.49, *SE* = .08, *t* = -6.45, *p* < .001. Second, a regression was performed to test for significant relations between perceived social support and depression, anxiety, and stress. These relations were found to be statistically significant, *b* = -.26, *SE* = .09, *t* = -2.79, *p* < .01, *b* = -.24, *SE* = .09, *t* = -2.57, *p* < .05, and, *b* = -.30, *SE* = .11, *t* = -2.60, *p* < .05, respectively.

Three mediational analyses were performed to investigate if parents' perceived social support mediated the relation between family burden and negative mental health outcomes when controlling for income and level of education. Bootstrapping analysis was used to estimate confidence intervals of the indirect effect, enabling the determination of significant mediation.

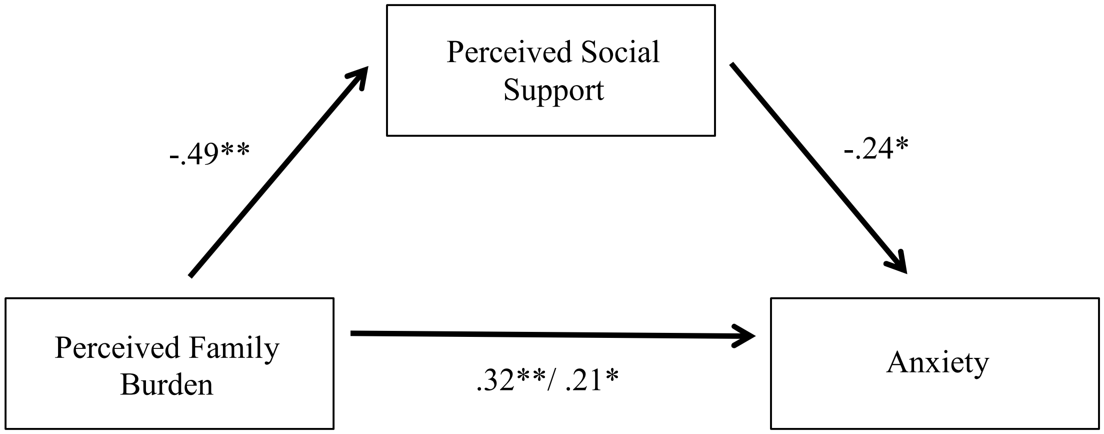
The first mediation analysis tested whether the effect of parents' perceived family burden on their depression would be mediated by their perceived social support when controlling for income and level of education. A bootstrapping procedure with 5000 samples was used to estimate the standard error and confidence intervals of the indirect effect. Statistical analysis confirmed that parents' perception of the degree of social support available significantly partially mediated the relation between their ratings of the demands of the child's epilepsy on the family and their self-reported depression, *b* = .13, *SE* = .06, *CI* = .03, .25 (Figure 3).



Note: Values indicate standardized regression coefficients (**p* < .05, ***p* < .01)

Figure 3. Standardized regression coefficients for the relation between perceived family burden and parental depression as mediated by perceived social support

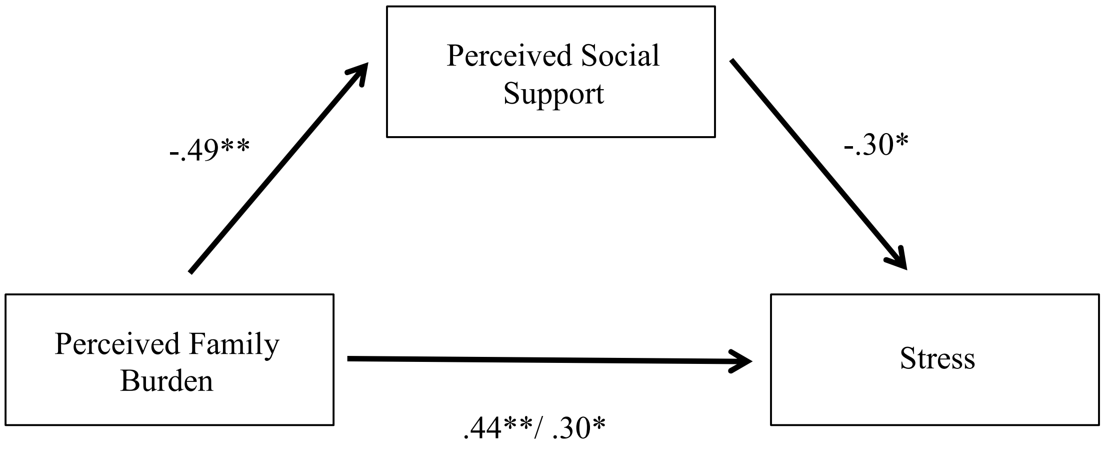
The second mediation analysis indicated that parents' perception of the degree of social support partially mediated the relation between their ratings of the effects of the child's illness on family burden and their self-reported anxiety, (*CI* = .03, .23) (Figure 4).



Note: Values indicate standardized regression coefficients (**p* < .05, ***p* < .01)

Figure 4. Standardized regression coefficients for the relation between perceived family burden and parental anxiety as mediated by perceived social support

The third mediation analysis revealed that the relation between parents' ratings of the effect of the child's illness on family burden and parents' self-reported stress was partially mediated by parents' perception of available social support, (*CI* = .03, .29) (Figure 5).



Note: Values indicate standardized regression coefficients (**p* < .05, ***p* < .01)

Figure 5. Standardized regression coefficients for the relation between perceived family burden and parental stress as mediated by perceived social support

DISCUSSION

Child Disability

As expected, in parents of children with epilepsy, greater levels of perceived child disability were related to higher levels of depression and anxiety. Surprisingly, the perception of child disability was not related to the level of stress in parents of children with epilepsy.

Child Disability and Outcome Measures with Emotion-Focused Coping as a Mediator

Contrary to Hypothesis 1, increased parental perceptions of their children's disability did not result in greater use of emotion-focused coping in parents of children with epilepsy. While this result precluded mediational analysis, the direct effect of emotion-focused coping on parental depression suggested that use of emotion-focused coping is related to low the levels of depression, but not stress or anxiety in parents of children with epilepsy. This finding is significant because it differs from past research in the Netherlands (Rodenburg, et al., 2007; van Andel et al., 2001), and Taiwan (Mu, Kuo & Chang, 2005; Mu, 2005), which indicated that the use of emotion-focused coping in parents of children with epilepsy was related to increased self-reported parent stress and depression.

The combination of a lack of mediation but the significant direct effect between emotion-focused coping and reductions in mental health outcomes may have been the result of high use of emotion-focused coping across the sample population. For instance, mothers from this sample may have already been using support-based Facebook groups as an online support system to gain others' understanding (Baum, 2004), share experiences, and vent emotions (Han & Belcher, 2001), all components of emotion-focused coping. Additionally, Nguyen, Pertini, and Kettler (2015), found that individuals who were more comfortable sharing their emotions reported greater use of emotion-focused coping. As such, across all perceived levels of child disability, these individuals may have felt more comfortable expressing their emotions, found greater comfort in doing so, and therefore used more emotion-focused coping behaviors.

Child Disability and Outcome Measures with Social Support Coping as a Mediator

Inconsistent with Hypothesis 2, increased parental perceptions of their child's disability did not result in greater use of social support coping in parents.

Baum (2004) reported that 88% of parents of children with disabilities utilized online support groups with the aim of receiving social support. Similar to the emotion-focused coping, the effect of perceived child disability on social support coping may have been insignificant because the current study's sample is representative of individuals who are already high in support seeking, which reduced the ability to detect differences (Baum, 2004).

However, the direct effect of social support coping on parental depression suggests that the use of social support as a coping behavior is related to lower levels of parental depression, but not stress or anxiety. This result is consistent with Shore et al. (2002) finding that parents who used social support at higher frequencies had lower levels of depression.

Child Disability and Outcome Measures with Perceived Social Support as a Mediator

As predicted in Hypothesis 3, the relation between perception of child disability and depression and anxiety was mediated by perceived social support. This model suggests that as parents' perception of the severity of their child's disability increases, their perception of social support decreases. Consequently, a reduction in perceived social support was related to increased self-reported depression and anxiety symptomatology. Further, this result indicated that increasing a parent's level of perceived social support could help reduce the level of anxiety and depression in parents of children with epilepsy.

This finding is consistent with previous research by Rodenburg et al. (2007). They found that in the Netherlands, perceived social support felt by parents of children with epilepsy was related to lower levels of depression. Additionally, this finding expands on research by Rodenburg et al. (2007) in two ways. First, it suggests that parents' perceptions of the social support they are receiving may reduce parental anxiety. Second, perceived social support, rather than the perception of the severity of the child's disability is the main contributor to parents' depression and anxiety.

Unexpectedly, perception of child disability was not significantly related to the level of stress in parents and therefore could not be used in the mediational analysis. In this sample, however, and consistent with Rodenburg et al. (2007), parents' increasing perception of social support was related to reductions in parental stress.

Family Burden

As expected, parents' perceptions of their child's epilepsy as a burden on the family were related to higher levels of depression, anxiety, and stress. The relation between perceptions of family burden and increased stress is consistent with findings from Buelow et al. (2006), who reported that having a child with epilepsy restricted the activities of the family, which produced greater parental stress

Family Burden and Outcome Measures with Emotion-Focused Coping and Social Support Coping as Mediators

Note: The direct effect of this relation between emotion-focused and social support coping was discussed previously in the disability section.

Disproving hypothesis 4 and 5, parents' perceptions of family burden were not associated with emotion-focused or social support coping behaviors. As such, mediational analyses were unable to be performed. This finding, as discussed previously, may have been the result of the sample population's high use of emotion-focused and social support coping (Baum, 2004). Additionally, this sample of participants may have utilized higher levels of emotion-focused coping because they found it to be helpful in reducing depression. For example, Nguyen, Pertini, and Kettler (2015) reported that individuals who were more comfortable sharing their emotions reported greater use and more success in reducing anxiety.

The differences in the effect of emotion-focused coping on mental health outcomes found in this study compared to prior research (Rodenburg, et al., 2007; van Andel et al., 2001), suggests that future studies that disaggregate this measure of coping may be able to provide greater understanding of specific components of emotion-focused coping behaviors that affect mental health outcomes.

Family Burden and outcome Measures with Perceived Social Support as a Mediator

Regarding Hypothesis 6, the relation between the perception of family burden and depression/anxiety/stress was partially mediated by perceived social support. This finding indicated that, in addition to perceived family burden, perceived social support partially contributed to the level of depression, anxiety, and stress in parents of children with epilepsy.

One reason perceived social support might not yield full mediation in this relation is because the child's epilepsy affects family processes beyond those associated with social support. For example, the perceived burden placed on the family may be a result of child behavioral problems that interfere with familial communication. For instance, the child may have increased behavioral problems such as higher levels of aggression (Alfstad et al., 2011; Austin & Caplan, 2007). Attending to these behaviors may reduce time that parents would otherwise have allocated to family relationships. This decrease may have resulted in decreased martial satisfaction (Rodenburg et al., 2007), or satisfaction with other children within the family (Austin et al., 2002). Furthermore, parenting a child with epilepsy has been associated with decreases in democratic parenting (Akey et al., 2011) and higher directive parenting styles (Chapieski et al., 2005), which in turn, lowers parent child relationship quality (Rodenburg et al., 2005b). Finally, there may be a social stigma associated with having a child with epilepsy (Wirrel et al., 2008). This concern has been shown to restrict the activities of the family and affect parents’ mental health more than the severity of the epilepsy itself (Lv et al., 2009; Shore et al., 2002).

In addition to the relationship strains the child’s epilepsy may induce, families may feel an increased economic burden of caring for a child with epilepsy that inhibits social activities (Thomas & Bindu, 1999). For example, Karakis et al. (2014) found that the number of anti-epilepsy drugs a child was taking was related to the amount of perceived caregiver burden, while seizure frequency, duration, and type of seizure were not significantly related to burden. Lv et al. (2009) found that the cost of epilepsy treatment significantly affected caregiving parents’ ratings of the quality of their life. These effects suggest that in addition to behavioral problems and relationship consequences associated with a child’s epilepsy, the cost of treating the disease may be related to higher levels of depression, stress, and anxiety.

Limitations and Future Research

The use of self-reported questionnaires via an online interface in this study precluded control over factors that can affect participants’ responding. The factors involve, for example, the length of the questionnaires, attending to other children, or other family distractions may have reduced parents’ ability to give their full attention to each questionnaire. Further, the adoption of a common method approach, in which measurements only consisted of self-reported questionnaires, potentially limited the study’s ability to treat significant correlations as resulting from the relation between the constructs that the measures are intended to assess rather than the variance potentially introduced by the utilization of a single method of measurement (Podsakoff, P., Mackenzie & Podsakoff, 2003).

Another potential limitation of the current design was the recruitment of individuals, as all participants were identified and recruited through online message boards and Facebook groups. While many lower income individuals now have access to devices, Yardi and Bruckman (2012) found that these individuals were less likely to understand how to use the device and had less time with the device because of shared use among family members. As evidenced in the sample's demographic characteristics, restricting the questionnaires to an online form produced a sample with average household income of between $60,000 and $69,000, higher than the average of $46,326 in the United States (DeNavas-Walt, 2010). To account for this difference, each mediational model controlled for level of income and educational attainment. To avoid similar sampling problems, future studies could employ a more traditional recruitment method, such as mailing out questionnaires.

Furthermore, the current design was cross-sectional in nature. As such, it remains unclear whether the effects of an individual's assessment of their child's disability, the perceived burden it places on the family, coping behaviors, and perceived social support on parental mental health persist over time. Parents may or may not adjust to the difficulties associated with caring for a child with epilepsy. For example, parents' level of support or family burden may increase or decrease, or their attitudes regarding their child's disability may change. In one study, Austin and McDermott (1988) offered some evidence for parental change over time. They found that parental attitudes became more positive the longer their child had epilepsy. Future research could utilize a longitudinal design to determine how coping patterns of parents with epileptic children change over time as they learn to manage the disease. One goal of this design would be to examine, for example, whether changes in parents' ability to manage their child's disease would alter their coping and perception of support rating and thereby their levels of stress, anxiety, or depression.

In summary, this investigation both confirms and adds to previous work on the mental health impacts of caring for a child with a chronic disease. The results from this study agree with the findings from Shore et al. (2002) and Ireys and Silver (1996), which suggested that the effect of the disease's impact on the day-to-day family functioning has a greater effect on maternal mental health than the severity of the illness. Further, it suggests that low levels of perceived social support may explain the relation between the severity of their child's disability and parents' mental health outcomes, such as depression and anxiety. Last, it suggests that although parents of children used Facebook as a means of social support, they may not have perceived the group as a form of adequate social support. The next step in the research is to refine coping measures and obtain measures of change over time.

REFERENCES

Akay, A. P., Kurl, S. H., Ozek, H., Cengizhan, S., Emiroglu, N., & Ellidokuz, H. (2011). Maternal reactions to a child with epilepsy: Depression, anxiety, parental attitudes and family functions. *Epilepsy Research*, (95), 213-220.

Akimoto, H. (2004). What I learnt from studying epilepsy: Epileptology and myself. *Psychiatry and Clinical Neurosciences, 58*(2), 101-109.

Alfstad, K. Å., Clench□Aas, J., Van Roy, B., Mowinckel, P., Gjerstad, L., & Lossius, M. I. (2011). Psychiatric symptoms in norwegian children with epilepsy aged 8–13 years: Effects of age and gender? *Epilepsia, 52*(7), 1231-1238.

Appleton, R. E. (1995). Treatment of childhood epilepsy. *Pharmacology & Therapeutics, 67*(3), 419-431.

Austin, J. K., & Caplan, R. (2007). Behavioral and psychiatric comorbidities in pediatric epilepsy: Toward an integrative model. *Epilepsia, 48*(9), 1639-1651.

Austin, J. K., Dunn, D. W., Caffrey, H. M., Perkins, S. M., Harezlak, J., & Rose, D. F. (2002). Recurrent seizures and behavior problems in children with first recognized seizures: A prospective study. *Epilepsia, 43*(12), 1564-1573.

Austin, J. K., Risinger, M. W., & Beckett, L. A. (1992). Correlates of behavior problems in children with epilepsy. *Epilepsia, 33*(6), 1115-1122.

Baki, O., Erdogan, A., Kantarci, O., Akisik, G., Kayaalp, L., & Yalcinkaya, C. (2004). Anxiety and depression in children with epilepsy and their mothers. *Epilepsy & Behavior, 5*(6), 958-964.

Baum, L. S. (2004). Internet parent support groups for primary caregivers of a child with special health care needs. *Pediatric Nursing, 30*(5), 381-401

Berg, A. T., Caplan, R., & Hesdorffer, D. C. (2011). Psychiatric and neurodevelopmental disorders in childhood-onset epilepsy. *Epilepsy & Behavior, 20*(3), 550-555.

Berkovic, S. F., Mulley, J. C., Scheffer, I. E., & Petrou, S. (2006). Human epilepsies: Interaction of genetic and acquired factors. *Trends in Neurosciences, 29*(7), 391-397.

Bhalla, D., Godet, B., Druet-Cabanac, M., & Preux, P. (2011). Etiologies of epilepsy: A comprehensive review.

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*(4), 208-215.

Buelow, J. M., McNelis, A., Shore, C. P., & Austin, J. K. (2006). Stressors of parents of children with epilepsy and intellectual disability. *Journal of Neuroscience Nursing, 38*(3), 147-155.

Caplan, R., Siddarth, P., Gurbani, S., Hanson, R., Sankar, R., & Shields, W. D. (2005). Depression and anxiety disorders in pediatric epilepsy. *Epilepsia, 46*(5), 720-730.

Carlton-Ford, S., Miller, R., Nealeigh, N., & Sanchez, N. (1997). The effects of perceived stigma and psychological over-control on the behavioural problems of children with epilepsy. *Seizure, 6*(5), 383-391.

Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*(2), 267.

Chapieski, L., Brewer, V., Evankovich, K., Culhane-Shelburne, K., Zelman, K., & Alexander, A. (2005). Adaptive functioning in children with seizures: Impact of maternal anxiety about epilepsy. *Epilepsy & Behavior, 7*(2), 246-252.

Chiou, H. H., & Hsieh, L. P. (2008). Parenting stress in parents of children with epilepsy and asthma. *Journal of Child Neurology, 23*(3), 301-306. doi:10.1177/0883073807308712 [doi]

Chun, M. (2004). *Effects of Cultural Values and Behaviors in Sociocultural Stress and Coping among Korean-American and Korean Caregivers,*

Cohen, S., & Hoberman, H. M. (1983). Positive events and social supports as buffers of life change stress1. *Journal of Applied Social Psychology, 13*(2), 99-125.

Cross, J. H., Kluger, G., & Lagae, L. (2013). Advancing the management of childhood epilepsies. *European Journal of Paediatric Neurology, 17*(4), 334-347.

Curing the epilepsies. (2013). (No. 13 6120). National Institutes of Health.

Cushner-Weinstein, S., Dassoulas, K., Salpekar, J. A., Henderson, S. E., Pearl, P. L., Gaillard, W. D., & Weinstein, S. L. (2008). Parenting stress and childhood epilepsy: The impact of depression, learning, and seizure-related factors. *Epilepsy & Behavior, 13*(1), 109-114.

Davies, S., Heyman, I., & Goodman, R. (2003). A population survey of mental health problems in children with epilepsy. *Developmental Medicine & Child Neurology, 45*(5), 292-295.

de Boer, H. M. (2010). Epilepsy stigma: Moving from a global problem to global solutions. *Seizure, 19*(10), 630-636.

DeNavas-Walt, C. (2010). Income. Poverty, and health insurance coverage in the United States (2005). DIANE Publishing

Elger, C. E., & Schmidt, D. (2008). Modern management of epilepsy: A practical approach. *Epilepsy & Behavior, 12*(4), 501-539.

Falk, N. H., Norris, K., & Quinn, M. G. (2014). The factors predicting stress, anxiety and depression in the parents of children with autism. *Journal of Autism and Developmental Disorders, 44*(12), 3185-3203.

Fisher, B. M., Segal, D. L., & Coolidge, F. L. (2003). Assessment of coping in cognitively impaired older adults: A preliminary study. *Clinical Gerontologist, 26*(3-4), 3-12.

Fisher, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, J. H., Elger, C. E., . . . Glynn, M. (2014). ILAE official report: A practical clinical definition of epilepsy. *Epilepsia, 55*(4), 475-482.

Fisher, R. S., Boas, W. v. E., Blume, W., Elger, C., Genton, P., Lee, P., & Engel, J. (2005). Epileptic seizures and epilepsy: Definitions proposed by the international league against epilepsy (ILAE) and the international bureau for epilepsy (IBE). *Epilepsia, 46*(4), 470-472.

Friedrich, W. N., Greenberg, M. T., & Crnic, K. (1983). A short-form of the questionnaire on resources and stress. *American Journal of Mental Deficiency,*

Grant, J. S., Elliott, T. R., Giger, J. N., & Bartolucci, A. A. (2001). Social problem-solving abilities, social support, and adjustment among family caregivers of individuals with a stroke. *Rehabilitation Psychology, 46*(1), 44.

Han, H., & Belcher, A. E. (2001). Computer-mediated support group use among parents of children with cancer – an exploratory study. *Computers in Nursing*, 19(1), 27-33.

Hawley, C. A., Ward, A. B., Magnay, A. R., & Long, J. (2003). Parental stress and burden following traumatic brain injury amongst children and adolescents. *Brain Injury, 17*(1), 1-23.

Hayes, A. F., & , M. (2013). The relative trustworthiness of inferential tests of the indirect effect in statistical mediation analysis: Does method really matter? *Psychological Science, 24,* 1918-1927.

Heitzmann, C. A., & Kaplan, R. M. (1988). Assessment of methods for measuring social support. *Health Psychology, 7*(1), 75.

Honey, E., Hastings, R. P., & McConachie, H. (2005). Use of questionnaire on resources and stress (QRS-F) with parents of young children with autism. *Autism*, 9(3), 243-252.

Hosseini, N., Sharif, F., Ahmadi, F., & Zare, M. (2010). Striving for balance: Coping with epilepsy in iranian patients. *Epilepsy & Behavior, 18*(4), 466-471.

Ireys, H. T., & Silver, E. J. (1996). Perception of the impact of a child's chronic illness: Does it predict maternal mental health? *Developmental and Behavioral Pediatrics*, *17*(2), 77-83

Iseri, P. K., Ozten, E., & Aker, A. T. (2006). Posttraumatic stress disorder and major depressive disorder is common in parents of children with epilepsy. *Epilepsy & Behavior, 8*(1), 250-255.

Jones, F., & Bright, J. (2001). *Stress: Myth, theory, and research* Pearson Education.

Ju, S. H., Chang, P. F., Chen, Y. J., Huang, C. C., & Tsai, J. J. (1990). Parental attitude and adjustment to childhood epilepsy. *Zhonghua Minguo Xiao Er Ke Yi Xue Hui Za Zhi [Journal].Zhonghua Minguo Xiao Er Ke Yi Xue Hui, 31*(2), 103-109.

Karakis, I., Cole, A. J., Montouris, G. D., San Luciano, M., Meador, K. J., & Piperidou, C. (2014). Caregiver burden in epilepsy: Determinants and impact. *Epilepsy Research and Treatment*, 2014, 1-9.

Kerne, V., & Chapieski, L. (2015). Adaptive functioning in pediatric epilepsy: Contributions of seizure-related variables and parental anxiety. *Epilepsy & Behavior, 43*, 48-52.

Kleinman, A., Wang, W., Li, S., Cheng, X., Dai, X., Li, K., & Kleinman, J. (1995). The social course of epilepsy: Chronic illness as social experience in interior china. *Social Science & Medicine, 40*(10), 1319-1330.

Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: The updated sociocultural stress and coping model. *The Journals of Gerontology.Series B, Psychological Sciences and Social Sciences, 65B*(1), 5-13. doi:10.1093/geronb/gbp096 [doi]

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping* (1st ed.). New York: Springer Publishing Company.

Lim, K., & Tan, C. (2014). Epilepsy stigma in asia: The meaning and impact of stigma. *Neurology Asia, 19*(1), 1-10.

Loring, D. W. (2010). History of neuropsychology through epilepsy eyes. *Archives of Clinical Neuropsychology : The Official Journal of the National Academy of Neuropsychologists, 25*(4), 259-273. doi:10.1093/arclin/acq024 [doi]

Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the depression anxiety stress scales (DASS) with the beck depression and anxiety inventories. *Behaviour Research and Therapy, 33*(3), 335-343.

Lv, R., Wu, L., Jin, L., Lu, Q., Wang, M., Qu, Y., & Liu, H. (2009). Depression, anxiety and quality of life in parents of children with epilepsy. *Acta Neurologica Scandinavica, 120*(5), 335-341.

Mu, P. (2005). Paternal reactions to a child with epilepsy: Uncertainty, coping strategies, and depression. *Journal of Advanced Nursing, 49*(4), 367-376.

Mu, P., Kuo, H., & Chang, K. (2005). Boundary ambiguity, coping patterns and depression in mothers caring for children with epilepsy in taiwan. *International Journal of Nursing Studies, 42*(3), 273-282.

Neal, E. G., Chaffe, H., Schwartz, R. H., Lawson, M. S., Edwards, N., Fitzsimmons, G., . . . Cross, J. H. (2008). The ketogenic diet for the treatment of childhood epilepsy: A randomised controlled trial. *The Lancet Neurology, 7*(6), 500-506.

Ngugi, A. K., Kariuki, S. M., Bottomley, C., Kleinschmidt, I., Sander, J. W., & Newton, C. R. (2011). Incidence of epilepsy: A systematic review and meta-analysis. *Neurology, 77*(10), 1005-1012. doi:10.1212/WNL.0b013e31822cfc90 [doi]

Nguyen, S., Pertini, M., & Kettler, L. (2015). Parental cognitive appraisals and coping behaviours following child's epilepsy diagnosis: A qualitative study. *Clinical Child Psychology and Psychiatry, 20*(1), 20-38. doi:10.1177/1359104513494089 [doi]

Patterson, T. L., Semple, S., Shaw, W., Yu, E., He, Y., Zhang, M., . . . Grant, I. (1998). The cultural context of caregiving: A comparison of alzheimer's caregivers in shanghai, china and san diego, california. *Psychological Medicine, 28*(05), 1071-1084.

Podsakoff, P. M., MacKenzie, S. B., & Podsakoff, N. P. (2003). Common method bias in behavioral research: A critical review of the literature and recommended remedies. *Journal of Applied Psychology, 88*(5), 879-903.

Porter, B. E., & Jacobson, C. (2013). Report of a parent survey of cannabidiol-enriched cannabis use in pediatric treatment-resistant epilepsy. *Epilepsy & Behavior, 29*(3), 574-577.

Reilly, C., Kent, E., & Neville, B. G. (2013). Review: Psychopathology in childhood epilepsy. *Child and Adolescent Mental Health, 18*(2), 65-75.

Rodenburg, R., Meijer, A. M., Deković, M., & Aldenkamp, A. P. (2005). Family factors and psychopathology in children with epilepsy: A literature review. *Epilepsy & Behavior, 6*(4), 488-503.

Rodenburg, R., Meijer, A. M., Deković, M., & Aldenkamp, A. P. (2007). Parents of children with enduring epilepsy: Predictors of parenting stress and parenting. *Epilepsy & Behavior, 11*(2), 197-207.

Rodenburg, R., Stams, G. J., Meijer, A. M., Aldenkamp, A. P., & Dekovic, M. (2005). Psychopathology in children with epilepsy: A meta-analysis. *Journal of Pediatric Psychology, 30*(6), 453-468. doi:jsi071 [pii]

Sander, J. W. (2003). The epidemiology of epilepsy revisited. *Current Opinion in Neurology, 16*(2), 165-170.

Savage, N. (2014). Epidemiology: The complexities of epilepsy. *Nature, 511*(7508), S2-S3.

Shore, C. P., Austin, J. K., & Dunn, D. W. (2004). Maternal adaptation to a child's epilepsy. *Epilepsy & Behavior, 5*(4), 557-568.

Shore, C. P., Austin, J. K., Huster, G. A., & Dunn, D. W. (2002). Identifying risk factors for maternal depression in families of adolescents with epilepsy. *Journal for Specialists in Pediatric Nursing, 7*(2), 71-80.

Shorvon, S. D. (2011). The causes of epilepsy: Changing concepts of etiology of epilepsy over the past 150 years. *Epilepsia, 52*(6), 1033-1044.

Shorvon, S. D. (2011). The etiologic classification of epilepsy. *Epilepsia, 52*(6), 1052-1057.

Smith, L. E., Greenberg, J. S., & Seltzer, M. M. (2012). Social support and well-being at mid-life among mothers of adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(9), 1818-1826.

Smith, P. (2012).
Introduction: The causes of epilepsy *Epilepsia, 53*(4), 1-2.

Soltanifar, A., Ashrafzadeh, F., Mohareri, F., & Mokhber, N. (2011). Depression and anxiety in iranian mothers of children with epilepsy. *Iranian Journal of Child Neurology, 6*(1), 29-34.

Spielberger, C. D. (1983). *Manual for the State-Trait Anxiety Inventory*. Palo Alto: Consulting Psychologcial Press.

Stein, R. E., & Riessman, C. K. (1980). The development of an impact-on-family scale: Preliminary findings. *Medical Care, 18*(4), 465-472.

Taylor, S. E., Sherman, D. K., Kim, H. S., Jarcho, J., Takagi, K., & Dunagan, M. S. (2004). Culture and social support: Who seeks it and why? *Journal of Personality and Social Psychology, 87*(3), 354.

Thomas, S. V., & Bindu, V. B. (1999). Psychosocial and economic problems of parents of children with epilepsy. *Seizure, 8*, 66-69.

van Andel, J., Westerhuis, W., Zijlmans, M., Fischer, K., & Leijten, F. S. (2011). Coping style and health-related quality of life in caregivers of epilepsy patients. *Journal of Neurology, 258*(10), 1788-1794.

Vermaes, I., Janssens, J., Mullaart, R., Vinck, A., & Gerris, J. (2008). Parents' personality and parenting stress in families of children with spina bifida. *Child: Care, Health and Development, 34*(5), 665-674.

Williams, J., Steel, C., Sharp, G. B., DelosReyes, E., Phillips, T., Bates, S., . . . Griebel, M. L. (2003). Parental anxiety and quality of life in children with epilepsy. *Epilepsy & Behavior, 4*(5), 483-486.

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

Wood, L. J., Sherman, E. M., Hamiwka, L. D., Blackman, M. A., & Wirrell, E. C. (2008). Maternal depression: The cost of caring for a child with intractable epilepsy. *Pediatric Neurology, 39*(6), 418-422.

World Health Organization (WHO). (2014). Epilepsy: Fact Sheet No 999. (2012).

Yardi, S., & Bruckman, A. (2012). Income, race, and class: Exploring socioeconomic differences in family technology use. *Proceeding of the SIGCHI Conference on Human Factors in Computing Systems*, 3041- 3050.

Yong, L., Cheng-Ye, J., Jiong, Q., & Zhang, Z. (2008). Parental anxiety and quality of life of epileptic children. *Biomedical and Environmental Sciences, 21*(3), 228-232.

APPENDIX A

PARTICIPANT INFORMATION LETTER AND CONSENT

Hello, My name is Jeffrey Carlson and I am a graduate student in psychology at Arizona State University. I am conducting research on how caring for a child with epilepsy effects parents and families. My research consists of a series of questionnaires that take approximately 45 minutes. Participation in the study will help us learn more about the ways in which parents react to and manage the day-to-day interactions in families that have with a child with epilepsy. The information that parents provide may be helpful in creating more sensitive and useful information that can be shared with the epilepsy community. If you are willing to voluntarily participate please follow this link to the study. Thank you for your time and consideration.

https://www.surveymonkey.com/s/ParentingChildrenwithEpilepsy

Jeffrey Carlson
Jmcarls5@asu.edu

We are hoping to learn more about the ways in which parents react to and manage the day-to-day interactions in families that have with a child with epilepsy. All participants must be over 18 years of age in order to eligible to participate in the study. The information that parents provide may be helpful in creating more sensitive and useful information that can be shared with the epilepsy community.

If you decide to participate, then your participation will last approximately 45 minutes. You will be asked to complete several questionnaires. There are no known risks from taking part in this study, but in any research, there is some possibility that you may be subject to risks that have not yet been identified.

All information obtained in this study is strictly confidential. The results of this research study may be used in reports, presentations, and publications, but the researchers will not identify you. In order to maintain confidentiality of your records, Dr. Paul A. Miller and Jeffrey Carlson will store data in a secure location on a password protected computer hard disk so that only the principle investigator and the graduate student will have access to it.

Participation in this study is completely voluntary. It is ok for you to say no. Even if you say yes now, you are free to say no later, and withdraw from the study at any time. Your decision will not affect your relationship with Arizona State University or otherwise cause a loss of benefits to which you might otherwise be entitled. Note: Some of the questions are sensitive in nature. You have the right not to answer any question, and to stop participation at any time during the survey.

Any questions you have concerning the research study or your participation in the study, before or after your consent, will be answered by Dr. Paul A. Miller, New College of Interdisciplinary Arts & Sciences, Arizona State University, P.O. Box 37100, Phoenix, AZ, 85069-7100, Mail Code 3501, Email: icpam@asu.edu: 602-543-6014. If you have questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk; you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity

Do you agree to the above terms? By selecting Yes, you are giving consent that you are willing to answer the questions in this study.

APPENDIX B

COPE INVENTORY

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel, when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Then respond to each of the following items by blackening one number on your answer sheet for each, using the response choices listed just below. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU--not what you think "most people" would say or do. Indicate what YOU usually do when YOU experience a stressful event.

1 = I usually don't do this at all

2 = I usually do this a little bit

3 = I usually do this a medium amount

4 = I usually do this a lot

1. I try to grow as a person as a result of the experience.
2. I turn to work or other substitute activities to take my mind off things.
3. I get upset and let my emotions out.
4. I try to get advice from someone about what to do.
5. I concentrate my efforts on doing something about it.

6. I say to myself "this isn't real."

7. I put my trust in God.

8. I laugh about the situation.

9. I admit to myself that I can't deal with it, and quit trying.

10. I restrain myself from doing anything too quickly.

11. I discuss my feelings with someone.

12. I use alcohol or drugs to make myself feel better.

13. I get used to the idea that it happened.

14. I talk to someone to find out more about the situation.

15. I keep myself from getting distracted by other thoughts or activities.

16. I daydream about things other than this.

17. I get upset, and am really aware of it.

18. I seek God's help.

19. I make a plan of action.

20. I make jokes about it.

21. I accept that this has happened and that it can't be changed.

22. I hold off doing anything about it until the situation permits.

23. I try to get emotional support from friends or relatives.

24. I just give up trying to reach my goal.

25. I take additional action to try to get rid of the problem.

26. I try to lose myself for a while by drinking alcohol or taking drugs.

27. I refuse to believe that it has happened.

28. I let my feelings out.

29. I try to see it in a different light, to make it seem more positive.

30. I talk to someone who could do something concrete about the problem.

31. I sleep more than usual.

32. I try to come up with a strategy about what to do.

33. I focus on dealing with this problem, and if necessary let other things slide a little.

34. I get sympathy and understanding from someone.

35. I drink alcohol or take drugs, in order to think about it less.

36. I kid around about it.

37. I give up the attempt to get what I want.

38. I look for something good in what is happening.

39. I think about how I might best handle the problem.

40. I pretend that it hasn't really happened.

41. I make sure not to make matters worse by acting too soon.

42. I try hard to prevent other things from interfering with my efforts at dealing with this.

43. I go to movies or watch TV, to think about it less.

44. I accept the reality of the fact that it happened.

45. I ask people who have had similar experiences what they did.

46. I feel a lot of emotional distress and I find myself expressing those feelings a lot.

47. I take direct action to get around the problem.

48. I try to find comfort in my religion.

49. I force myself to wait for the right time to do something.

50. I make fun of the situation.

51. I reduce the amount of effort I'm putting into solving the problem.

52. I talk to someone about how I feel.

53. I use alcohol or drugs to help me get through it.

54. I learn to live with it.

55. I put aside other activities in order to concentrate on this.

56. I think hard about what steps to take.

57. I act as though it hasn't even happened.

58. I do what has to be done, one step at a time.

59. I learn something from the experience.

60. I pray more than usual.

APPENDIX C

DEPRESSION ANXIETY STRESS SCALE

Please read each statement and circle a number 0, 1, 2 or 3 that indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree, or some of the time

2 Applied to me to a considerable degree, or a good part of time

3 Applied to me very much, or most of the time

1 I found myself getting upset by quite trivial things

2 I was aware of dryness of my mouth

3 I couldn't seem to experience any positive feeling at all

4 I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)

5 I just couldn't seem to get going

6 I tended to over-react to situations

7 I had a feeling of shakiness (e.g., legs going to give way)

8 I found it difficult to relax

9 I found myself in situations that made me so anxious I was most relieved when they ended

10 I felt that I had nothing to look forward to

11 I found myself getting upset rather easily

12 I felt that I was using a lot of nervous energy

13 I felt sad and depressed

14 I found myself getting impatient when I was delayed in any way (e.g., elevators, traffic lights, being kept waiting)

15 I had a feeling of faintness

16 I felt that I had lost interest in just about everything

17 I felt I wasn't worth much as a person

18 I felt that I was rather touchy

19 I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical exertion

20 I felt scared without any good reason

21 I felt that life wasn't worthwhile

22 I found it hard to wind down

23 I had difficulty in swallowing

24 I couldn't seem to get any enjoyment out of the things I did

25 I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)

26 I felt down-hearted and blue

27 I found that I was very irritable

28 I felt I was close to panic

29 I found it hard to calm down after something upset me

30 I feared that I would be "thrown" by some trivial but unfamiliar task

31 I was unable to become enthusiastic about anything

32 I found it difficult to tolerate interruptions to what I was doing

33 I was in a state of nervous tension

34 I felt I was pretty worthless

35 I was intolerant of anything that kept me from getting on with what I was doing

36 I felt terrified

37 I could see nothing in the future to be hopeful about

38 I felt that life was meaningless

39 I found myself getting agitated

40 I was worried about situations in which I might panic and make a fool of myself

41 I experienced trembling (e.g., in the hands)

42 I found it difficult to work up the initiative to do things

APPENDIX D

THE QUESTIONNAIRE ON RESOURCES AND STRESS SCALE - FREDRICH EDITION

This questionnaire deals with feelings about your family. There are many blanks on the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions, even if they do not seem to apply. If it is difficult for you to decide True (T) of False (F), answer in terms of what you or your family feel or do most of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please begin. Remember to answer all of the questions.

1. _______ doesn't communicate with others of his/her age group
2. Other members of the family have to do without things because of _______
3. Our family agrees on important matters
4. I worry about what will happen to _______ when I can no longer take care of him/her
5. The constant demand for care for _______ limit growth and development of someone else in our family
6. I have accepted the fact that _______ may have to live out his/her life in some special

   setting (e.g. institution or group home)
7. _______ is able to feed himself/herself
8. I have given up things I really wanted to do in order to care for _______
9. _______ is able to fit into the family social group
10. Sometimes I avoid taking _______ out in public

11. In the future, our family’s social life will suffer because of increased responsibilities and financial stress
12. It bothers me that _______will always be this way
13. I feel tense whenever I take _______ out in public
14. I can go visit with friends whenever I want
15. Taking _______on a vacation spoils pleasure for the whole family
16. _______ knows his/her own address
17. The family does as many thing together now as we ever did
18. _______ is aware who he/she is
19. I get upset with the way my life is going
20. Sometimes I feel very embarrassed because of _______
21. _______ doesn't do as much as he/she should be able to do
22. It is difficult to communicate with _______because he/she has difficulty what is being said to him/her
23. There are many places where we can enjoy ourselves as a family when _______comes along
24. _______ is overprotected
25. _______ is able to take part in games or sports
26. _______ has too much time on his/her hands
27. I am disappointed that _______does not lead a normal life
28. Time drags for _______especially free time
29. _______can’t pay attention for very long
30. It is easy for me to relax

31. I worry about what will be done with _______ when he/she gets older

32. I get almost too tired to enjoy myself

33. One of the things I appreciate about _______ is his/her confidence

34. There is a lot of anger and resentment in our family

35. _______ is able to go to the bathroom alone

36. _______ cannot remember what he/she says from one moment to the next

37. _______ can ride a bus

38. It is easy to communicate with _______

39. The constant demand to care for _______ limit my growth and development

40. _______ accepts himself/herself as a person

41. I feel sad when I think of _______I often worry about what will happen to
_______ when I can no longer care for him/her

42. People can’t understand what _______ tries to say

43. Caring for _______ puts a strain on me

44. Members of our family get to do the same kind of things other families do

45. _______ will always be a problem to us

46. _______ is able to express his/her feelings to others

47. _______ has to use a bedpan or a diaper

48. I rarely feel blue

APPENDIX E

INTERPERSONAL SUPPORT EVALUATION LIST

This scale is made up of a list of statements each of which may or may not be true about you. For each statement check “definitely true” if you are sure it is true about you and “probably true” if you think it is true but are not absolutely certain. Similarly, you should check “definitely false” if you are sure the statement is false and “probably false” is you think it is false but are not absolutely certain.

1. There are several people that I trust to help solve my problems.

___definitely true (3) ___definitely false (0)□___probably true (2) ___probably false (1)

2. If I needed help fixing an appliance or repairing my car, there is someone who would help me.

___definitely true (3) ___definitely false (0)□___probably true (2) ___probably false (1)

3. Most of my friends are more interesting than I am.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

4. There is someone who takes pride in my accomplishments.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

5. When I feel lonely, there are several people I can talk to.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

6. There is no one that I feel comfortable to talking about intimate personal problems.

___definitely true (3) ___definitely false (0)□___probably true (2) ___probably false (1)

7. I often meet or talk with family or friends.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

8. Most people I know think highly of me.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

9. If I needed a ride to the airport very early in the morning, I would have a hard time finding someone to take me.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

10. I feel like I'm not always included by my circle of friends.

___definitely true (3) ___definitely false (0)□___probably true (2) ___probably false (1)

11. There really is no one who can give me an objective view of how I'm handling my problems.

___definitely true (3) ___definitely false (0)□___probably true (2) ___probably false (1)

12. There are several different people I enjoy spending time with.

___definitely true (3) ___definitely false (0)□___probably true (2) ___probably false (1)

13. I think that my friends feel that I'm not very good at helping them solve their problems.

___definitely true (3) ___definitely false (0)□___probably true (2) ___probably false (1)

14. If I were sick and needed someone (friend, family member, or acquaintance) to take me to the doctor, I would have trouble finding someone.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

15. If I wanted to go on a trip for a day (e.g., to the mountains, beach, or country), I would have a hard time finding someone to go with me.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

16. If I needed a place to stay for a week because of an emergency (for example, water or electricity out in my apartment or house), I could easily find someone who would put me up.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

17. I feel that there is no one I can share my most private worries and fears with.

___definitely true (3) ___definitely false (0)☐___probably true (2) ___probably false (1)

18. If I were sick, I could easily find someone to help me with my daily chores.

___definitely true (3) ___definitely false (0)☐___probably true (2) ___probably false (1)

19. There is someone I can turn to for advice about handling problems with my family.

___definitely true (3) ___definitely false (0)☐___probably true (2) ___probably false (1)

20. I am as good at doing things as most other people are.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

21. If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

22. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.

___definitely true (3) ___definitely false (0)☐___probably true (2) ___probably false (1)

23. If I needed an emergency loan of $100, there is someone (friend, relative, or acquaintance) I could get it from.

___definitely true (3) ___definitely false (0)☐___probably true (2) ___probably false (1)

24. In general, people do not have much confidence in me.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

25. Most people I know do not enjoy the same things that I do.

___definitely true (3) ___definitely false (0)☐___probably true (2) ___probably false (1)

26. There is someone I could turn to for advice about making career plans or changing my job.

___definitely true (3) ___definitely false (0)☐___probably true (2) ___probably false (1)

27. I don't often get invited to do things with others.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

28. Most of my friends are more successful at making changes in their lives than I am.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

29. If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc.).

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

30. There really is no one I can trust to give me good financial advice.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

31. If I wanted to have lunch with someone, I could easily find someone to join me.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

32. I am more satisfied with my life than most people are with theirs.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

33. If I was stranded 10 miles from home, there is someone I could call who would come and get me.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

34. No one I know would throw a birthday party for me.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

35. It would me difficult to find someone who would lend me their car for a few hours.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

36. If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

37. I am closer to my friends than most other people are to theirs.

___definitely true (3) ___definitely false (0)□___probably true (2) ___probably false (1)

38. There is at least one person I know whose advice I really trust.

___definitely true (3) ___definitely false (0)□___probably true (2) ___probably false (1)

39. If I needed some help in moving to a new house or apartment, I would have a hard time finding someone to help me.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

40. I have a hard time keeping pace with my friends.

___definitely true (3) ___definitely false (0) ___probably true (2) ___probably false (1)

APPENDIX F

IMPACT ON FAMILY SCALE

Having children can change people's lives. Here are some statements that people have made about living with an ill child. For each statement, indicate whether at the present time you would strongly agree (4) , agree (3), disagree (2), or strongly disagree (1) with the statement.

The rating scale is as follows:

4 Strongly agree

3 Agree

2 Disagree

1 Strongly disagree

1. The illness is causing financial problem for the family
2. Time is lost form work because of hospital appointment
3. I am cutting down the hours I work to care for my child
4. Additional income is needed in order to cover medical expenses
5. I stopped working because of my child's illness
6. Because of the illness, we are not able to travel out of the city
7. People in the neighborhood treat us specially because of my child's illness
8. We have little desire to go out because of my child's illness
9. It is hard to find a reliable person to take care of my child
10. Sometimes we have to change plans about going out at the last minute because of my child's state
11. We see family and friends less because of the illness
12. Because of what we have shared we are closer as a family

13. Sometimes I wonder whether my child should be treated “specially” or the same as a normal child
14. Me relatives have been understanding and helpful with my child
15. I think about not having anymore children because of the illness
16. My partner and I discuss my child’s problems together
17. We try to treat my child as if he/she were a normal child
18. I don’t have much time left over for other family members after caring for my child
19. Relatives interfere and think they know what's best for my child
20. Our family gives up things because of my child’s illness
21. Fatigue is a problem for me because of my child’s illness
22. I live form day to day and don’t plan for the future
23. Nobody understands the burden I carry
24. Traveling to the hospital is a strain on me
25. Learning to manage my child’s illness has made me fee better about myself
26. I worry about what will happen to my child in the future when he/she grows up, when I am not around