Testing the Efficacy of the Creating Opportunities for Parent Empowerment (COPE) Intervention During Hospital to Home Transition: Empowering Parents of Children with Epilepsy and Other Neurological Conditions

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Testing the Efficacy of the Creating Opportunities for Parent Empowerment (COPE) Intervention During Hospital to Home Transition: Empowering Parents of Children with Epilepsy and Other Neurological Conditions

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Abstract

Background: Parents of children with epilepsy and other neurological conditions live with a feeling of constant uncertainty. The uncertainty associated with caring for a child with epilepsy and other neurological conditions produces stress, which leads to decreased parental belief in caregiving skills, anxiety, and depression, ultimately altering parental functioning resulting in an increase in child behavioral problems. The stress associated with caring for a child with epilepsy and other neurological conditions is unlike caring for children with other chronic conditions. Epilepsy and other neurological conditions are unpredictable and there are often no warning signs prior to an acute event. This unpredictability accompanied with stigma results in social isolation and impacts family functioning. In addition, children with epilepsy have a higher rate of psychological co-morbidities and behavior problems when compared to children with other chronic conditions. This produces an additional burden on the parents and family.

Study Design: This randomized controlled trial tested the efficacy of the COPE intervention for parents of children with epilepsy and other neurological conditions. This intervention was administered at three intervals: 1) during hospital admission in writing and by audiotape, MP3 download, or Podcast; 2) three days following hospital discharge by telephone; and 3) four to six weeks after hospital discharge in writing and by audiotape, MP3 download, or Podcast.

Results: Forty-six parents of children admitted to the inpatient neuroscience unit at Boston Children's Hospital participated in the study. Several study limitations resulted in an inadequate sample size to obtain the power necessary to reach statistically significant results for a majority of the research questions. A one-between, one-within multivariate analysis of variance (MANOVA) revealed that the main effect of time was significant for differences in state anxiety for both the Usual Care Group and the Intervention Group, F, (1, 20) = 9.86, p = .005, indicating that state anxiety for both groups combined was more pronounced during the hospitalization. A one-between, one-within MANOVA demonstrated that the effect of the interaction between time and group was significant for internalized behavior assessment system score only (p=.037) as the Usual Care Group reported a significant decrease in internalizing behavior scores in their children over time.

Conclusions: Findings from this study have significant implications for clinical practice and future research. Parents of children with neurological conditions often struggle to manage a constant feeling of uncertainty in their daily lives. Nurses possess the knowledge and expertise necessary to identify the psychosocial needs of these parents and provide education and support as needed. Future research should focus on designing interventions to meet the needs of these families and develop strategies to help improve the quality of life for both the parent and child living with a neurological condition.

Key Words: pediatric epilepsy, nursing, coping, parents of children with epilepsy

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Dedication

This dissertation is dedicated to my parents for their love and support throughout the years. Without their encouragement, I never would have made it this far.

Finally, I would like to dedicate this dissertation to my husband, Rob and children, Jake and Harper, who I love with all of my heart. To my husband who has stood by me through all of the trials and tribulations of the past seven years. It has not always been easy, but his love and support have never faltered and for that I am truly grateful. To Jake who is truly a miracle, in more ways than one. I feel blessed and thankful for every day that I have you in my life. To Harper, whose smiling face gives me joy, may you always know in your heart that anything you want out of life is possible.

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CHAPTER I

Statement of Problem

Pediatric nurses are frequently faced with the challenge of caring for children with chronic conditions and their families. Childhood epilepsy is a chronic condition that has a significant impact on the individual child and their family system. Each year, 45,000 children and adolescents under 15 years of age will develop epilepsy (Epilepsy Foundation of America®, 2011). Epilepsy is unlike many other common chronic childhood conditions in that it is unpredictable and often associated with an unknown prognosis (Berg et al., 2005; Oostrom, Schouten, Kruitwagen, Peters, & Jennekens-Schinkel, 2001). Seizures often occur without any warning and can be difficult to manage requiring unplanned and frequent hospitalizations, clinic visits, and medical procedures. Parents of children with epilepsy are faced with the challenge of providing a safe environment for their child on a daily basis while also maintaining positive family functioning without knowing when, where, or if a seizure will occur. The feeling of uncertainty increases when symptoms are not consistent and cannot be predicted (Mishel & Braden, 1988). Seizures are frightening to witness and may also be associated with stigma when they occur outside of the home. This places an additional burden on the family resulting in social isolation (Wagner et al., 2009). Parents of children with epilepsy want to provide a healthy environment for their child at home and in the context of healthcare interventions; however, as they strive to move forward, they struggle with ongoing feelings of uncertainty related to the unpredictable nature of this condition (Mu, 2005).

Parental uncertainty often results in an increased level of stress that can negatively affect a parents' belief in their own parenting skills needed to care for their child living with epilepsy. Parents experience uncertainty because epilepsy is a condition with an unpredictable course and

the child's condition can often change day-to-day. This uncertainty experienced by parents can lead to a certain level of stress (Stewart & Mishel, 2000). The stress parents experience when their child is acutely ill often impairs their ability to cope and they are unsure or unable to support their child through the experience. This parental stress reaction can result in high levels of anxiety and depression, which can influence parental confidence in caregiving skills (Chapieski et al., 2005; Tzoufi et al., 2005; Keller & Honig, 2004).

Decreased parent confidence in the ability to anticipate the needs of a hospitalized child has been referred to in the literature as parental belief (Melnyk et al., 2006; Melnyk et al., 2001a). Decreased parental belief in these caregiving skills can have a profound impact on the child's ability to cope, which may contribute to behavioral challenges in the child with epilepsy. The interaction between parental belief in caring for a child with epilepsy and subsequent behavioral problems with the child can affect family functioning and quality of life for the child (Buelow, McNelis, Shore, & Austin, 2006). Pediatric nurses have the ability to assess parental coping skills especially when parents are dealing with the stress of having a child with formidable healthcare needs. Nurses can teach parents strategies to facilitate their own coping and support lifestyle modifications to provide for the child's needs and care and ultimately enhance family life. These new coping skills could result in less psychological co-morbidity. Thus, it is important to explore the valid and effective interventions designed to address coping strategies to decrease the stress and uncertainty among families living with pediatric epilepsy.

Although many researchers (Buelow et al., 2006; Austin, Dunn, Johnson, & Perkins, 2004; Carlton-Ford, Miller, Nealeigh, & Sanchez, 1997) have identified the relationship between effective parental coping and the improved psychosocial outcomes of acutely ill children, little has been done to validate interventions that may be effective in improving the coping strategies

of parents caring for a child with a chronic condition such as epilepsy (Melnyk et al., 2004; Melnyk et al., 2001a ; Melnyk, 2000).

One intervention that has been successful in improving psychosocial outcomes of parents of acutely ill children is Creating Opportunities for Parent Empowerment (COPE). Melnyk, Alpert-Gillis, Hensel, Cable-Beiling, and Rubenstein (1997) developed the COPE intervention to enhance the coping strategies of parents of previously healthy children who were admitted to an intensive care unit for the management of an acute condition. The COPE intervention teaches parents how their child might react to being hospitalized and then instructs parents on how to best respond to their child's needs. Evaluation of this intervention has been positive for parents of children who experience hospitalization for an acute condition. Parents who participated in the COPE intervention reported decreased levels of stress and anxiety, fewer depressive symptoms, and increased confidence in their parenting abilities when compared to parents who did not participate in the intervention (Melnyk et al., 2004; Melnyk & Alpert-Gillis, 1998; Melnyk et al., 1997).

The strategies espoused in the COPE intervention have been shown to be successful when a child is hospitalized with an acute illness, but have yet to be implemented in facilitating the transition from hospital to home for children with chronic conditions. The transition from hospital to home is especially stressful for parents as there is a considerable amount of uncertainty related to the possible adjustments in their child's medical care as well as not knowing how to help children cope with experiences they may have had while in the hospital. This is an important area where information is lacking since children with chronic conditions will continue to experience repeated hospitalizations over the course of their condition. Although not introduced with parents whose children have a chronic condition, the past success

and logical design of the COPE intervention offers an opportunity to replicate the intervention with parents of children with chronic conditions undergoing hospitalization as well. The COPE intervention may be particularly well suited for parents of children with epilepsy, as epilepsy is associated with repeated hospitalizations (Jacoby, Snape, & Baker, 2005) and numerous psychological and physiological co-morbidities (Bazil, 2004). Due to uncertainty and repeated hospitalizations, epilepsy is one of the most stress producing pediatric conditions for parents to manage (Mu, 2008; Rodenburg, Meijer, Dekovic, & Aldenkamp, 2007).

The purpose of this study was to test the efficacy of the modified COPE intervention with parents of children with epilepsy who required hospitalization for diagnosis or treatment of their condition.

Significance of Problem

The literature supports the premise that parental coping strategies directly affect the child's health related quality of life (Melnyk, 2000). When faced with a stressful situation, a person is forced to identify strategies to allow them to effectively cope with the situation (Lazarus & Folkman, 1984). According to Lazarus and Folkman (1984), coping consists of two sub-categories; emotional (expressive) coping and functional coping (problem solving). In emotional coping, people's emotions are produced based on their appraisal of the situation and this reflects how they think they are managing in the situation (Folkman & Lazarus, 1985). Emotional coping often results in behaviors that include seeking emotional support, wishful thinking, or self-blame (Folkman & Lazarus, 1985). In functional coping, people search for ways to change their situation if they feel it can be changed. Individuals use a combination of both of these strategies when faced with stressful situations (Folkman & Lazarus, 1985).

Parents of children with chronic conditions are faced with stressful situations on a daily basis and they often lack the skills necessary to effectively cope with that stress. Increased stress and decreased coping strategies can result in a negative or depressed mood state in the parent. Depression and anxiety in mothers of children with epilepsy have been associated with decreased health-related quality of life in children with epilepsy (Williams et al., 2003).

Inappropriate or inadequate coping strategies may also lead to increased levels of stress; another very important stressor parents identify is that they sense their parenting role has been altered (Cohen, 1993; Mu & Tomlinson, 1997). Parents of children with chronic conditions have a difficult time maintaining a successful parenting role (Friedman, Holmbeck, Jandasek, Zuckerman, & Abad, 2004). Parents identify the most stressful aspect of caring for a child with a chronic condition is the uncertainty in how best to help their child cope with their condition (Melnyk, 2000). Keller and Honig (2004) reported that the child's temperament, severity of the disability, associated behavior problems, and parental role restrictions often add to the degree and intensity of parental stress. Ultimately ineffective parenting skills can emerge (Friedman et al., 2004). How parents learn to cope with their child's chronic condition is important because it directly affects the quality of life of their child.

Baca, Vickrey, Caplan, Vassar, and Berg (2011) reported that health-related quality of life in children with epilepsy was not related to seizure severity but more significantly influenced by psychological co-morbidities including behavior problems, anxiety, and depression. Epilepsy is a unique chronic childhood condition in that it is often associated with significant behavior problems (Austin & Dunn, 2000). This is an additional burden for parents as managing behavior problems in the child with epilepsy is necessary in order to have a positive impact on quality of life (Baca et al., 2011).

Parental coping often influences these psychological co-morbidities. Parents who themselves have increased levels of anxiety and depression often have difficulty helping their children cope with a stressful situation. Children who continue to have difficulty coping with their diagnosis of epilepsy have significant negative psychosocial outcomes as adults including, lower socioeconomic status, difficulty maintaining employment, and a lower level of educational attainment (Sillanpaa, Haataja, & Shinnar, 2004; Shackelton, Kasteleijn-Nolst, Trenite de Craen, Vandenbroucke, & Westendorp, 2003). These factors in turn have significant societal implications as the annual direct and indirect costs of epilepsy in the United States are estimated to be $15.5 billion dollars (Hirtz et al., 2007).

In families with a child with a chronic condition the functioning of the entire family is affected by the child's condition. The ability of the family to function can be a significant predictor of how the child will adjust to their condition (Friedman et al., 2004). A child with a chronic condition can learn how to continue the day-to-day activities of a healthy childhood if the family is able to provide a supportive and nurturing environment.

A diagnosis of epilepsy in childhood has significant long-term consequences, regardless of the clinical severity of the disorder. Melnyk, Feinstein, Moldenhouer, and Small (2001b) reported that parental stress could be relieved if parents were taught what behaviors to expect from their child and how to respond appropriately. The ability to recognize available coping resources is an important part of self-regulation; therefore, the inability to recognize and utilize existing coping resources has a direct impact on parents' ability to obtain care for their child. The following study was designed to address the need for parents of children with epilepsy to understand the psychosocial effects of this chronic condition and how their role as a parent can facilitate positive coping strategies in their child.

Definitions

The following study variables were defined as follows:

Epilepsy

Epilepsy is a disorder that is characterized by the event of at least one epileptic seizure, but the abnormalities in the brain are such that the risk of experiencing another event in the future is likely (Fisher et al., 2005). This variable will be identified from examining the child's medical record and patient history for physiologic criteria, documented by an epileptologist, that meet the above definition.

Uncertainty

Uncertainty is a feeling related to the fear of the unknown. Parents of children with chronic conditions experience uncertainty because the nature of their child's condition does not allow them to be able to predict what the future may hold. This is significant as the constant feeling of uncertainty can result in psychological distress and stress on positive family functioning (Stewart & Mishel, 2000).

Stress

Stress refers to an uncomfortable emotional experience that has the potential to result in both physical and psychological manifestations. Although short-term stress may be beneficial, chronic stress often negatively affects a persons' well-being. Stressors refer to the antecedents of stress (American Psychological Association, 2013).

Parental Belief

Parental belief is defined as the amount of confidence a parent has in their ability to anticipate and respond appropriately to the needs of their hospitalized child (Melnyk, 1994). This variable will be measured by using the Parental Beliefs Scale (Melnyk, 1994). This scale

was developed by Melnyk (1994) to better characterize the extent to which child behavior and parental role confusion result in anxiety of the parent.

Depression

According to the *Diagnostic and Statistical Manual of Mental Disorders-IV-TR* (American Psychiatric Association, 2000), depression is defined as a continual feeling of sadness that results in a decreased interest in participating in daily activities. This variable will be measured by respondents' scores on the Beck Depression Inventory-II (BDI-II). Beck, Steer, and Brown (1996) developed the BDI-II as an instrument used to identify the presence or severity of depressive symptoms as outlined in the *Diagnostic and Statistical Manual of Mental Disorders –IV-TR.*

Anxiety

Anxiety is a multidimensional construct that consists of a state and a trait as well as a combination of both physical and mental symptoms that cannot be explained by an underlying medical condition (American Psychiatric Association, 2000). Anxiety can manifest itself as feelings of fear, worry, or nervousness. Physical symptoms are activated by the autonomic nervous system and often include; tachycardia, diarrhea, sweating, flushing, and dizziness (Spielberger, 1983). Trait anxiety can be defined as an individual's propensity to evaluate a situation as anxiety producing. State anxiety refers to the level of anxiety an individual is currently experiencing (Spielberger, 1983). This variable will be measured by respondents' scores on the State-Trait Anxiety Inventory. Spielberger (1983) developed this instrument to measure state and trait anxiety levels.

Child Behavior

Behavior is defined as both the disruptive and adaptive features of the child's response to living with epilepsy. Disruptive features will include: hyperactivity, aggression, anxiety, depression, tendency to be overly sensitive, immaturity, withdrawal, or problems with attention (Reynold & Kamphaus, 2002). Adaptive behaviors include: social skills, and the ability to adapt to changes in the environment (Reynolds & Kamphaus, 2002). This variable will be measured by the Behavior Assessment System for Children -2 Parent Report Scale (BASC2-PRS). Reynolds and Kamphaus (1992) developed this instrument to help parents identify and rate behavior problems in their children.

Parent

Any woman or man who serves as the primary caregiver of a biologic or adopted child who has a diagnosis of epilepsy.

Creating Opportunities for Parent Empowerment (COPE)

Creating Opportunities for Parent Empowerment (COPE) is a psychoeducational program developed to enhance the coping skills in children and their parents after a period of hospitalization (Melnyk, 1994). This program and respective measurement instrument is fully described in Chapter 2.

Usual Care

Standard nursing care delivered to children and their parents during any hospitalization for increased seizure activity on the inpatient neuroscience unit at Boston Children's Hospital.

Assumptions Based on Existing Knowledge

The following assumptions were made explicit for the purpose of this investigation:

1. Parenting a child with epilepsy is stressful and results in anxiety, depression, and decreased belief in parental ability to respond to the needs of their child, which ultimately leads to an increase in child behavior problems.
2. As individuals, mothers and fathers experience different levels of stress, anxiety, depression, and parent confidence, which collectively have different effects on child behavior.
3. Interventions designed to teach mothers and fathers coping strategies that help their child adapt to living with a chronic condition will result in positive coping in both the child with epilepsy and his or her mother and/or father.
4. Participants will respond truthfully and accurately when reporting their parental beliefs, symptoms of depression and anxiety and the ratings they ascribe to their child's behavior.

Research Questions and Hypotheses

The overall purpose of the study was to test the efficacy of the COPE intervention with parents of children with epilepsy. The study tested the following research questions and hypotheses:

RQ1**.** Will parents receiving the COPE intervention demonstrate more belief in their parenting skills post-treatment compared to parents receiving usual care?

H1**.** Parents receiving the COPE intervention will demonstrate more belief in their parenting skills post-treatment compared to parents receiving usual care.

RQ2**.** Will parents receiving the COPE intervention demonstrate lower clinical depression scores post-treatment compared to parents receiving usual care?

H2. Parents receiving the COPE intervention will demonstrate lower clinical depression scores post-treatment compared to parents receiving usual care.

RQ3. Will parents receiving the COPE intervention demonstrate significantly less state anxiety post-treatment compared to parents receiving usual care?

H3. Parents receiving the COPE intervention will demonstrate significantly less state anxiety post-treatment compared to parents receiving usual care.

RQ4. Will the children of parents receiving the COPE intervention demonstrate fewer behavior problems compared to children of parents receiving usual care?

H4. Children of parents receiving the COPE intervention will demonstrate fewer behavior problems compared to children of parents receiving usual care.

CHAPTER II

Theoretical Basis

The COPE intervention was originally developed for parents of children who were hospitalized in an intensive care unit following an acute illness episode. The design of the intervention was based on the combination of three theoretical frameworks including: control theory, the emotional-contagion hypothesis, and self-regulation theory. Control theory proposes that people try to change their behavior when they perceive a discrepancy between what they believe to be a normal experience, and what is actually currently occurring in their lives (Carver, 1979). People with an adequate sense of control can adjust their daily activities to compensate for any changes that may be occurring in their lives. The problem arises when people cannot change their behaviors because of their anxiety or environmental constraints (Carver & Scheier, 1982).

The emotional-contagion hypothesis proposes that the psychological state of the parent greatly affects that of the child. VanderVeer (1949) first described the concept of parents transmitting their anxiety or negative feelings to their children. This concept is very important when trying to promote the child's adjustment to living with a chronic condition, such as epilepsy. For a child to successfully cope with epilepsy, they rely on the support of their parents. It is crucial to help parents find ways to deal with their own mood state as it is known that children as young as toddler age can sense these feelings and become anxious themselves (Melnyk, 1995).

"Self-regulation refers to self-generated thoughts, feelings, and actions that are planned and cyclically adapted to the attainment of personal goals" (Zimmerman, 2000, p.14). Essentially, self-regulation is the process by which people adapt to change. It is considered to be

cyclical because there is a continuous interaction between person, behavior, and environment. The person begins by sensing a change in their environment. They then need to alter their behavior to adapt to this new change (Zimmerman, 2000). Self-regulation theory has been studied within several scientific disciplines to try and explain how it is that people or organisms adapt to stressful situations in order to achieve their goals.

The self-regulation theory was originally proposed by Nerenz and Leventhal (1983) "to describe and predict how people cope with stressful health threats" (p. 13). The assumption is that "patients can make decisions about coping and managing their experience and set their own standards for success based on what is important to them" (Johnson, Fieler, Wlasowicz, Mitchell, & Jones, 1997, p. 1041). Common health goals include being emotionally comfortable and resuming normal daily activities, but each individual defines these terms differently and therefore each person needs to go through the process separately.

According to self-regulation theory, adapting behavior to deal with an experience occurs in a series of stages. The first of these stages is what Nerenz and Leventhal (1983) refer to as representation. This stage is crucial because people interpret the experiences associated with their illness and then determine specific actions to take based on their representation of the situation. The emphasis is on the fact that the individual person is responsible for interpreting the situation. This illness representation is based on information gathered through one's sensations during the event.

The second stage is the coping or action planning stage. This is when the person decides what to do in the situation. The action chosen is directly influenced by the illness representation. "People use their perceptions and interpretations of their experience to regulate their responses and behavior" (Johnson, 1999, p. 436). People often develop their response by using a cognitive

schema in order to "anticipate our experience, to select what we attend to, to plan what we will do, and to guide our behavior" (Johnson, 1999, p. 436). This schema informs the patient on what they should expect during the upcoming event. It also helps to predict what will happen when similar events occur in the future. The schema, initially formed by the illness representation created in stage one, is used by the person to draw on information stored in their memory about similar past experiences. This allows the person to evaluate actions used in the past as either having been successful or not. Successful actions could be tried first in the new situation. Being able to draw from past experiences enables the person to develop a response that will yield a successful outcome. By doing this, the person is able to establish their personal goal for the situation or what they expect the outcome to be. The person is then able to prioritize resources needed to reach the defined goals (Johnson et al., 1997).

The third stage consists of the person's continued appraisal of the situation (Nerenz & Leventhal, 1983). If the person feels that he or she has met their goals, then he or she views the chosen strategy as successful and it continues. However, reevaluation of the response occurs if the goal has not been attained, and changes are made as necessary. A person will change their action plan when "a discrepancy between the person's goal or expected outcome and what exists motivates the person to take action to reduce the discrepancy" (Johnson, 1999, p. 436).

The process of self-regulation may further be divided into two pathways. The first pathway is the regulation of emotional response, and the second is the regulation of a functional response to a possible threat. Although these pathways are described as being parallel to one another, there is often overlap between the two. The interesting point to consider here is that patients are likely to experience negative emotions if they are told to expect them. For example, if a patient is told that a particular procedure will be distressing, the patient will look for and

focus on the distressing aspect until it is found (Johnson et al., 1997). Interventions, therefore, should be designed to encourage parents to help their children cope with medical procedures by deemphasizing the negative aspects and emphasizing the positive aspects of the intervention. Coping techniques that accomplish this can provide a more positive hospital experience.

The last important assumption to mention regarding this adaptive system is that it is arranged hierarchically from abstract to concrete. The abstract is similar to cognitive processing where the concrete relates to the process of coping (Nerenz & Leventhal, 1983). This idea is best illustrated by the use of the following example. An illness representation of epilepsy can be formed hierarchically with a label of epilepsy being abstract, and sensations of illness such as seizure exacerbation being the concrete representation.

Literature Review

A literature search was conducted using a variety of healthcare databases including; CINAHL, Medline, and PsychInfo. An initial search for articles using the term *epilepsy* resulted in over 70,000 articles. When the search term was refined to be specific for *pediatric epilepsy*, only 305 articles were found. All of the titles were reviewed to identify articles that were specific to parenting a child with epilepsy. Once significant studies were retrieved, the references within each of those articles were examined for possible relevance. Authors were then identified within the literature that had completed data-based research with this population and a search of additional citations by author was performed to identify any pertinent studies. The articles were then retrieved and examined for possible inclusion. The final sample was limited to articles published in English between 1995 and 2012. Only data-based research articles pertaining to the experience of parenting a child with epilepsy, the effect parenting abilities have on a child with epilepsy, or the effect of specific interventions directed to parents

of children with epilepsy were included. To obtain a comprehensive review, studies including one or both parents were included, and there was no restriction concerning age of the child or severity of their illness. Articles excluded were those that related to the medical management or diagnosis of a seizure disorder.

The purpose of this exclusion was to narrow the focus of the review to issues surrounding parenting. The final sample of literature focused on the experience of parenting a child with epilepsy, and how the parents' well-being effects the child's adjustment to his/her illness. Major themes from the literature were identified and their relationships are outlined in the figure below.

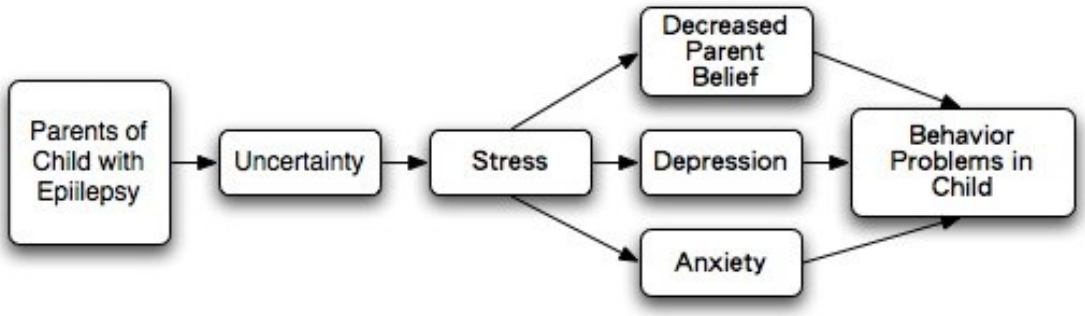

Figure 1. Effects of Parenting a Child with Epilepsy

Parenting a Child with Epilepsy

Not unlike parents of children with other chronic conditions, parents of children with epilepsy face many challenges on a day-to-day basis. However, it has been noted that parents of children with epilepsy experience higher levels of stress than parents of children with other chronic conditions (Chiou & Hsieh, 2008; Austin, 1988). This increased level of stress is often related to the constant uncertainty that is part of this unpredictable condition. Learning to cope with this uncertainty is a significant factor to consider since family coping has been directly linked to the developmental, social, and psychological outcomes of the child (Aytch, Hammond, & White, 2001). The family seems to have a larger influence on the child's well-being since

children with epilepsy tend to have an increased risk for developing complications, even if their seizures are well controlled (Carlton-Ford, et al., 1995; Mitchell, 1995; Austin, Smith, Risinger, & McNelis, 1994). Rodenburg, Meijer, Dekovic, and Aldenkamp (2006) found that children with epilepsy tended to have more psychopathology than children from the general population including depression and attention problems. This may be partially attributed to the fact that the emotional state of the parent can greatly affect the ability of the child to cope with his or her diagnosis of epilepsy, although underlying neurological issues and side effects of medication are known contributing factors (Modi, Ingerski, Rausch, & Glauser, 2011; Rodenburg, Wagner, Austin, Kerr & Dunn, 2011; Sherman et al., 2008).

Uncertainty

Uncertainty is a concept that has been studied by many scholars in relationship to both adults and children with a variety of conditions. The effects of uncertainty may differ depending on the diagnosis and trajectory of the illness. The uncertainty experienced by a parent of an acutely ill child is different from that of a parent whose child has a chronic condition. Uncertainty associated with a chronic condition is often a lifelong experience that needs to be incorporated into daily activities. Understanding the concept of uncertainty can help to design future interventions for parents of children with chronic conditions.

Cohen (1993) described different types of uncertainty experienced by parents including: existential, etiological, treatment, situational, biographical, and social. Within these categories the defining attributes of uncertainty emerge as: worrying about the child's future, having to make decisions without the proper information, having to adjust to an unclear parenting role, and not knowing what caused the condition in the first place.

At the time a child is initially diagnosed with a chronic condition, parents experience feelings of uncertainty related to how to adapt the family lifestyle to an unpredictable future. Moreover, the feeling of uncertainty does not end with the diagnostic phase because parents are confronted with the daily uncertainty of how their child's condition will present from one day to the next (Johnson, 2000). This is an important consideration since researchers have found that "uncertainty has the potential to disrupt the family's sense of control and normal state of functioning" (Sharkey, 1995, p.37). Sharkey (1995) found that uncertainty resulted from not knowing the etiology of the child's condition in the first place, and therefore not being able to predict the course of the disease process or the child's prognosis. Unfortunately, in pediatrics, healthcare professionals are often unable to determine the cause of the child's condition. This can be extremely frustrating for a family who is looking for an answer as to why their child has a particular diagnosis. With the underlying cause unknown, the health care team cannot predict how each individual child is going to respond to a certain treatment plan. Parents often state that they feel they could prepare themselves to deal with the future if they knew what to expect. This sense of being unable to anticipate the future only adds to the feeling of uncertainty.

In addition to being uncertain about the child's future, parents also experience an increased sense of worry whenever their child has a change in his or her health status. Parents often find themselves in a constant state of flux as they attempt to interpret cues from their child in order to make appropriate medical decisions (Clements, Copeland, & Loftus, 1990). When a child experiences a sudden change in their health status, parents have a difficult time altering their role in order to provide the support the child needs at the time. Therefore, to compensate for this not knowing, parents often cope by being vigilant in monitoring every aspect of their child's life (Burke, Kauffmann, Costello, & Dillon, 1991). This vigilance may become

hypervigilance and decrease the child's autonomy and initiative as they learn to adapt to life with a chronic condition.

Even if the child is at a stable point in their condition, parents always fear the child could have a relapse at any moment. Cohen (1995) found that although parents reported feeling "like a time bomb could go off at any time", they also recognized that uncertainty was worst at times of symptom exacerbation. Parents face certain challenges when children with chronic conditions experience exacerbations of symptoms or admissions to the hospital. When the child is discharged from the hospital, parents are often left feeling helpless and abandoned by the healthcare team (Kohlen, Beier, & Danzer, 2000). In order to be able to adequately address the feelings of uncertainty experienced by many parents, it is important for nurses and other providers to share what is known about potential exacerbations in terms of events and activities. This additional information enables the parent to better prepare for the future.

Parents worry whether or not the child will ever meet certain developmental milestones, and who will care for the child in the future when the parents are no longer able to do so (Monsen, 1999; Hirose & Ueda, 1990). These feelings of uncertainty often become overwhelming for the family. "As the uncertainty spreads into major life areas, the person is not able to eliminate it, and it functions to dismantle the person's view of self and of reality" (Mishel, 1999, p. 272). Once this occurs the family begins to alter their previous way of life. It is living with this constant feeling of not knowing that threatens to destroy the family structure because the lack of stability prevents the family from creating long-term plans or goals. For these reasons, chronic uncertainty has been identified as the single greatest psychological stressor experienced by parents caring for children with chronic conditions (Koocher, 1985).

It is equally important to identify if there are other events in the child's life that may result in feelings of uncertainty. These include; medical appointments, body variability, keywords and provocative questions, changes in therapeutic regimens, negative outcomes, new developmental demands, and worrying that occurs at nighttime. Mishel and Braden (1988) identified several antecedents to increased feelings of uncertainty. These include symptom pattern, event familiarity, and structure providers. Symptom pattern refers to the fact that when symptoms are consistent or somewhat predictable, there is less uncertainty. Event familiarity occurs after certain events have been experienced repeatedly over a period of time. Structure providers refers to the resources available to individuals to help them interpret a situation include education level, availability of social support, and exposure to credible authority. There is some evidence to support the idea that higher levels of education and cognitive capacity can help people effectively use information provided to them. Appropriate social support can actually facilitate the way parents perceive the patterns of their child's symptoms as well as the familiarity with events (Mishel & Braden, 1988). Credible authority refers to the amount of trust parents have in their healthcare providers and has been found to have a positive impact on lowering the amount of uncertainty experienced by parents (Sharkey, 1995; Clarke-Steffan, 1993; Mishel & Braden, 1988). The literature has shown that credible authority has a significant impact on feelings of uncertainty, which means nurses have a great deal of influence over the parental experience. Mishel (1999) identified nature of illness, unknown future, concept of self, lack of information, health care providers, and personality dispositions as factors that contribute to uncertainty. These findings are extremely helpful to the nurse caring for these families. Nurses may be able to identify situations that may heighten the feeling of uncertainty so that the nurse can intervene during those times.

Consequences of uncertainty include psychological distress, challenges to parental and family roles, and personal growth (Stewart & Mishel, 2000). "Uncertainty particularly seems to alter the parent's ability to appraise any subsequent threat to their child's health and to restrict their use of ordinary coping behaviors that they previously found to be effective in managing the parental role around issues concerning the child's health" (Cohen & Martinson, 1988, p. 91). Several researchers have identified a reliable association between increased levels of uncertainty and emotional or psychological difficulties (Mullins, Chaney, Balderson, & Hommel, 2000; Stewart & Mishel, 2000; Jessop & Stein, 1985). Clarke-Steffan (1993) found that uncertainty resulted in worry and preoccupation, a sense of vulnerability and a feeling of helplessness. It has also been found that uncertainty can threaten the family structure (Sharkey, 1995) and lead to chronic anxiety, hypochondriasis, non-compliance, marital and financial stress (Koocher, 1985).

Empirical referents of uncertainty in parenting a child with a chronic condition are related to family functioning. Most families survive living with chronic uncertainty by making decisions on a day-to-day basis. Sterken (1996) noted that uncertainty was evidenced by parents being unable to make decisions because they were unable to predict possible outcomes. Parents are therefore unable to plan for their own future and essentially become socially isolated. This isolation from family and friends is significant since it has been established that family support has an important role in decreasing uncertainty and allowing parents to process information.

Uncertainty is an undeniable part of caring for a child with a chronic condition. It can have detrimental effects on each of the parents and the family as a whole (Sharkey, 1995; Burke et al., 1991; Koocher, 1985). Since each individual child responds to a particular illness in a unique manner, it is impossible to rid parents of this feeling of not knowing. The literature provides many descriptions of uncertainty and caring for a chronically ill child, but there is very

little research that focuses on interventions designed to help alleviate some of the burden. This gap is a crucial area in which nurse researchers need to become involved. Nurses need to help parents learn to manage this uncertainty so they can bring a sense of normalcy back to their life and the life of their family.

Caring for a child with epilepsy results in a constant feeling of uncertainty due to the irregularity of seizure activity and the unpredictable trajectory of the condition. Uncertainty is associated with disruptions in family life, making the process of normalization difficult. Mu (2005) found that the uncertainty associated with parenting a child with epilepsy results in an increased level of stress, which alters the roles of family members. Because parents cannot predict when their child will have another seizure, they feel a loss of control and therefore become unsure of how to best meet their child's needs. The parent role they once knew is now altered. In turn, this loss of control over their child's seizure disorder decreases the family's ability to adjust to life with a child who has epilepsy (Mu, Wong, Chang, & Kwan, 2001).

Stress

Parenting a child with epilepsy can be a significant source of stress. Parents report that the first several months after the initial diagnosis of epilepsy are the most stressful (Austin et al., 2001). Stress associated with an initial diagnosis can continue for months, even years as parents process what the diagnosis and related caretaking responsibilities mean for their family. During this time parents experience a great deal of ongoing uncertainty surrounding their child's prognosis including, future seizures, possible developmental delays, and medical interventions (Oostrom et al., 2001). It is this uncertainty that contributes to parental stress. This stress from uncertainty tends to be unresolved and becomes an ongoing problem with which parents are forced to live. Cushner-Weinstein et al. (2008) surveyed 65 parents of children between the ages

of 7 and 16 years with epilepsy and found that 45% of the parents reported increase stress levels. Learning how to incorporate this constant uncertainty into day-to-day life results in an ongoing stress on the family system.

In semi-structured interviews with parents ($N = 20$) of adolescents with epilepsy, Buelow et al., (2006) found that as stress increases, family functioning decreases as evidenced by poor communication between parents, social isolation, and strained relationships between the child with epilepsy and their siblings. This parental stress places a strain on parent-child interactions (Austin et al., 2004). In their study, Shatla, Sayyah, Azzam, and Elsayed (2011) found that parental stress is directly related to child factors. They studied families ($N = 23$) of children with epilepsy between the ages of 9 and 12 years. They found that children with epilepsy place more demands on their parents, which results in increased levels of parental stress (Shatla et al., 2011).

Stress experienced by parents of children with epilepsy is often manifested in parental role restrictions, such as the inability to maintain discipline, leading to child behavior problems (Austin et al., 2004; Keller & Honig, 2004; Austin, Risinger, & Beckett, 1992). Behavior problems in children with epilepsy are an additional stressor for the parent. Wirrell, Wood, Hamiwka, and Sherman (2008) surveyed mothers ($N = 52$) of children with epilepsy ages 2 to 18 years and found that externalizing child behavior problems (i.e. - aggression, acting out) resulted in increased parental stress. Stress related to child behavior problems may be relieved if parents are taught what behaviors to expect from their child and how to respond to them appropriately.

Prolonged stress has a significant impact on the coping ability of parents (Melnyk et al., 2001b), and is positively correlated with decreased confidence in their parenting abilities and, or, depression. Increased parental stress also results in anxiety, which ultimately leads to an

overprotective parenting style and a further increase in child behavior problems (Wirrell et al., 2008).

Decreased Parental Belief

How parenting a child with a chronic condition alters parental functioning is a significant predictor of how the child will adjust to his or her illness (Mullins et al., 2007; Friedman, et al., 2004). Due to the uncertainty of an epilepsy diagnosis, parent functioning is disrupted because parents are faced with an unfamiliar situation. Parents find themselves abandoning previous roles as they struggle to determine how each family member is affected by their new situation (Mu & Chang, 2010) and this places the family in a state of chaos (Mu, 2008). Oostrom et al. (2001) found that 48% of the parents in their study were unable to continue what they considered to be habitual, or routine, parenting after their child was diagnosed with epilepsy. When parents change their normal parenting routines, children may feel that they are being told they are vulnerable and they become uncertain about their own future (Mullins et al., 2007).

Parental belief refers to the confidence a parent has in their ability to provide their own child with positive coping strategies. When a parent loses confidence in these caregiving skills, it has been referred to as decreased parental belief (Melnyk et al., 2006; Melnyk et al., 2001a). The stress of managing a child with epilepsy often results in parents' loss of confidence in their ability to know what best to do for their child (Rodenburg et al., 2011). Parents often change their previous parenting habits and this may have negative effects on the child. One common change is for the parent to adopt an overprotective parenting style. Aytch et al. (2001) reported that, "parenting tended to be characterized by heightened vigilance and monitoring of the child's activities, concerns about the ability of others to respond appropriately to seizures, and reluctance to leave the child in the care of relatives and friends" (p. 285). Parents of children

with epilepsy tend to become overprotective because they don't know how to explain their child's needs and necessary care to someone else. For one year Chapieski et al. (2005) followed mothers ($N = 56$) of children between the ages of 6 and 12 years who had been diagnosed with epilepsy in the previous six months. Over the course of this year they found that mothers became overprotective, resulting in a decrease in both independence and adaptive functioning in the child (Chapieski et al., 2005). Carlton-Ford et al. (1997) interviewed parents ($N = 37$) of children between the ages of 6 and 13 years with non-degenerative epilepsy. The researchers interviewed both parents and children separately and found that an increase in illness severity, perceived stigma, and disrupted family dynamics resulted in parents being overprotective, which frequently resulted in increased behavior problems in the child (Carlton-Ford et al., 1997).

Parents of children with epilepsy also report difficulty in dealing with behavior problems in their children. Externalizing behavior problems, such as aggression, in children with epilepsy are often related to parents' inability to maintain confidence in their parenting role (Rodenburg et al., 2006). Austin et al. (2004) conducted a study involving parents ($N = 224$) of children with new onset seizures. The researchers found that parents had less confidence about how to discipline their children resulting in more behavior problems. The researchers also found that supporting the child's autonomy and worrying less about the cause and potential effects of the seizures helped to decrease behavior problems (Austin et al., 2004).

Parents often have decreased parental belief in their ability to facilitate coping strategies in their child with epilepsy because they do not know how to recognize normal behavioral responses to living with a chronic condition. When parents learn the assessment skills necessary to understand the behaviors that their child with epilepsy might display, their belief in their own ability to parent a child with epilepsy may improve. This increase in parent self-confidence will

occur by teaching parents strategies to respond to the behaviors they may witness in their child as a response to illness related experiences (Melnyk, et al., 2001a; Melnyk, 1994).

Depression

The stress associated with caring for a child with epilepsy can result in high rates of mental health issues among parents (Tzoufi, et al., 2005). Studies have demonstrated that mothers of children with epilepsy have a higher frequency of psychological morbidity (Ferrari, 1989; Rutter, Graham, & Yule, 1970). Mu (2005) found that the uncertainty associated with the diagnosis of epilepsy resulted in maternal depression. Ferro, Avison, Campbell, and Speechley (2011) studied mothers ($N = 258$) of children between the ages of 4 and 12 years who had been diagnosed with epilepsy twenty-four months prior to the study. The researchers found that 30% to 38% of mothers in the study were at risk for clinical depression. The most important risk factor for depression in this study was having a child with cognitive delays (Ferro et al., 2011).

Having a parent with depression can have a significant impact on the coping abilities of the child with epilepsy. Parents with a depressed mood state are less responsive to their children's needs and often have problems with the parent child relationship, which ultimately results in the child developing aggression, anxiety, and depression (Low & Stocker, 2005). Rodenburg et al. (2006) surveyed mothers ($n = 81$) and fathers ($n = 10$) of children between the ages of 4 and 18 years with a diagnosis of epilepsy without evidence of co-morbid psychiatric illness. They found that 18% of parents scored in the mild to moderate range for depression and that depression was more common among parents of children with externalizing behavior problems (Rodenburg, et al., 2006). Shore, Austin, and Dunn (2004) conducted telephone interviews with mothers of children who had a diagnosis of epilepsy for at least six months. They found that internalizing behavior problems (i.e. - anxiety and depression) and decreased

parent confidence in how to manage the child's seizure disorder predicted depressive symptoms in the mother (Shore et al., 2004). Parental depression has a significant impact on the child and family's ability to cope and live with this chronic condition. Therefore, it is important to recognize how an altered mood state may affect the parents' ability to obtain the resources or support necessary to maintain the functioning of the family.

Gendolla and Brinkmann (2005) studied the effect of mood states in relation to the theory of self-regulation. They found that parents who had a negative mood state were unable to effectively mobilize necessary resources. The ability to access and use resources is an important part of self-regulation and has a direct impact on how well parents obtain necessary information and resources to care for their child. Limited ability to obtain resources, in addition to the everyday pressures and demands of caring for a child with a chronic condition, often results in parents experiencing depression and levels of stress that negatively affect parental functioning (Mu, 2005; Shore, Austin, Huster, & Dunn, 2002). Shore et al. (2002) surveyed mothers (N = 115) of children between the ages of 8 and 12 years who had been diagnosed with epilepsy for at least one year. The researchers found that "child illness severity, maternal perceptions of stigma, and greater numbers of child behavior problems were significantly positively correlated with maternal depression" (Shore et al., 2002, p. 76). In addition, uncertainty and ambiguity surrounding family boundaries and role assignments have been found to be significant predictors of depression in mothers of children with epilepsy (Mu, Kuo, & Chang, 2005; Mu, et al., 2001). Parents of children with epilepsy need to be provided with the resources to help them enhance their parenting skills in order to best support the child and family. Parents who are experiencing their own depressive symptoms may not be able to adequately support their child through a

number of stressful situations and experiences. The healthcare provider is in an ideal position to both recognize and address these issues.

Anxiety

The uncertainty that accompanies a diagnosis of epilepsy produces worry in parents that often affects quality of life for both the child and his or her family. Parental anxiety is often highest during the first few months after the diagnosis of epilepsy. This state anxiety results in parents being overprotective and isolating themselves and their children from a variety of social situations, including school sponsored activities (Williams et al., 2003; Aytch et al., 2001). Anxiety is another contributor to an overprotective parenting style, which decreases the child's ability to function in social situations (Chapieski et al., 2005). This overprotectiveness results in a decreased quality of life for the child with epilepsy (Yong, Chengye, & Jiong, 2006). Williams et al. (2003) studied mothers (n = 179) and fathers (n = 21) of children between the ages of 6 and 16 years who had a diagnosis of epilepsy for at least one year. They found increased parental anxiety to be a significant factor in the decreased quality of life of their child. They also found that this anxiety changed their parenting behaviors. Parents with increased levels of anxiety may restrict their child's activities and may alter sleeping arrangements for fear of nighttime seizure events (Williams et al., 2003).

Lv et al. (2009) conducted semi-structured interviews with parents (N = 263) of children with epilepsy between the ages of 6 and 18 years. They again found that these parents had an increased level of anxiety, which resulted in social isolation. The degree of anxiety was directly correlated with a decrease in reported quality of life (Lv et al., 2009).

Ongoing uncertainty is responsible for a large amount of parental state anxiety and can have a significant impact on the quality of life experienced by all members of the family. Self-

regulation theory can be used to address this uncertainty to help parents form a cognitive schema that they can use to monitor and better understand the stress of the child's diagnosis and care (Melnyk, 1995), ultimately improving quality of life.

Behavior Problems in Child

It has been demonstrated that children with epilepsy have an increased risk for behavior problems when compared to children with other chronic conditions (Rodenburg et al., 2011; Berg et al., 2005; Oostrom et al., 2001; Austin & Dunn, 2000). Children with epilepsy may exhibit externalizing behavior problems, such as acting out or demonstrating aggressive behavior, when their parents are overly stressed or anxious (Wirrell et al., 2008). Behavior problems noted in children with epilepsy, however, are most likely to be internalizing behaviors including a decreased attention span, anxiety, and depression (Chapieski, et al., 2005; Austin, 2004; Williams et al., 2003; Austin et al., 2001). Although there are many possible factors related to the increased incidence of depression among children with epilepsy, parental factors and poor family functioning seem to be a significant contributor.

There is a substantive amount of literature that demonstrates the effect parents have on their child's behavior. Children demonstrate an increase in behavior problems when the family is not functioning in a healthy manner. Family functioning is often affected by the level of parental stress and the degree to which parents feel in control over the family environment (Austin et al., 2004; Austin et al., 2001). Families who have a strong social support network and access to a variety of resources adapt better to having a child with epilepsy and these children show fewer behavior problems then children whose parents have less support (Austin et al., 1992).

Austin et al. (2004) studied parents (N = 224) of children with epilepsy between the ages of 4 and 14 years. They surveyed the parents within six weeks of initial seizure diagnosis and again twenty-four months later. They found that at baseline child behavior problems were associated with decreased parent confidence and a disorganized environment. At twenty-four months, they found that externalizing behavior problems in the child that were related to parent anxiety, poor child discipline practices, and parental ability to promote autonomy in the child (Austin et al., 2004). Thornton et al. (2008) asked parents (N = 82) to complete surveys regarding the behavior of both their child with epilepsy and their child without epilepsy. When compared to their normal sibling, children with epilepsy were noted by their parent to have a higher rate of internalizing behavior problems, which correlated with family dysfunction (Thornton et al., 2008).

The ability of parents to cope with their child's epilepsy diagnosis has many implications for how the child will adjust to living with their chronic condition. This in turn, has a tremendous impact on how the family functions as a whole. Interventions aimed at facilitating coping in parents have the potential of greatly influencing the lives of people living with this condition.

Intervention Studies

A literature search was conducted to identify interventions designed for families of children with epilepsy that addressed and/or measured psychosocial outcomes in both the child with epilepsy and their parents. This search was conducted using a variety of healthcare databases including; CINAHL, Medline, and PsychInfo. Search terms included combinations of *pediatric epilepsy*, *intervention*, and *parenting*. There were a limited number of studies that included both children and parents as participants in the intervention. The final sample was

limited to articles published in English between 1995 and 2012. Only data-based research articles pertaining to the psychosocial effects of specific interventions directed to parents and children with epilepsy were included. The identified studies are presented in Table1.

Table 1

Intervention Studies for Children with Epilepsy and Their Parents

Researchers & Sample	Design & Intervention	Variable of Interest	Measures	Findings	Gap In Nursing Knowledge
Austin, McNelis, Shore, Dunn, & Musick (2002) Sample: 9 children who had epilepsy for 2-12months, 7-13yrs, and their families.	Five-step nurse coached telephone intervention administered over 3-4 month time period.	Knowledge about epilepsy and seizure management Fears associated with epilepsy	Parent and Child Report of Psychosocial Care Scale Child Attitude Toward Illness Scale (CATIS) Family APGAR	Children had less general concerns, more knowledge, needed less information, and higher family functioning scores. Parents had more general knowledge, needed less information, and needed less social support.	Does not provide parents with education regarding how to help their children cope
Snead et al. (2002) Sample: 7 adolescents taking AED's who have had at least 1 seizure in the last 2 years, 13-17 yrs, had 1 parent willing to participate.	Group held for didactic 1 hr sessions each week for 6 weeks, parents also provided with self-study guide.	Child Depression Adolescent Quality of Life Child Anxiety	Child Depression Inventory (CDI) Quality of Life for Adolescents with Epilepsy (QOLIE-AD-48) Revised Children's Manifest Anxiety Scale (RCMAS)	No significant changes on measures though adolescents and parents verbally expressed finding the program helpful.	Did not include school age children with epilepsy Did not measure outcomes in parents

Table 1 cont.

Tieffenberg, Wood, Alonso, Tossutti, & Vicente (2000) Sample: 355 children with moderate to severe asthma or epilepsy, 6-15 yrs, and their parents.	Two group experimental design: 5 weekly 2 hour meetings with reinforcement meeting 2-6 months later.	Child Autonomy School Absenteeism Clinical Variables	Health Locus of Control Scale Sociocultural Survey Probability of Gain Technique	Children had improvement in knowledge, beliefs, attitudes, and behaviors; decreased fears about death and disruption in family life. Parents had increased knowledge.	Intervention only focused on medical management of the condition Psychological consequences for neither parent or child were addressed

"Be Seizure Smart" was developed by Austin et al. (2002) to provide information about epilepsy, address concerns and fears, and provide emotional support to parents of nine children between the ages of 7 and 13 who had epilepsy. The intervention consisted of a five-step nurse coached telephone intervention for both the child with epilepsy and their parents, which was administered over a three to four month time period. Results of the intervention indicated that the children had fewer general concerns, more knowledge, needed less information, and had higher family functioning scores. Parents likewise reported that they had more general knowledge, had fewer questions, and needed less social support (Austin et al., 2002). There were no statistically significant changes regarding parental concerns regarding the management of their child's seizure disorder, but this may be due to the very small sample size (Austin et al., 2002). The researchers did not test the long-term effects of this intervention, but this information should be included in future studies replicating this intervention.

Snead et al. (2004) developed a psychoeducational program for adolescents who had epilepsy and their parents. Seven adolescents completed this program with their parents, which

consisted of six one-hour content sessions regarding cognitive behavioral techniques, dietary needs, and medical aspects of epilepsy. Participants were also given educational materials from the Epilepsy Foundation of America®. Although both parents and adolescents reported the intervention to be helpful, pre and post measurement of quality of life, depression, and anxiety revealed no significant changes (Snead et al., 2004). The findings of this intervention are difficult to interpret because of significant study limitations. The adolescents enrolled in the study experienced a wide variety of seizure types (Snead et al., 2004). Seizure frequency and severity are known to have a significant impact on the amount of stress the family is experiencing. Another factor was the small sample size, which made it difficult to detect a significant change in the outcome measures (Snead et al., 2004).

Tieffenberg et al. (2000) conducted a randomized controlled trial to evaluate a program for 355 Spanish-speaking children between the ages of 6 and 15 who had asthma (n = 188) or epilepsy (n = 167). This program was administered in weekly two-hour sessions over a period of five weeks. Parents and children meet in separate groups, but were taught the same information including; learning about epilepsy, recognizing equilibrium, understanding treatment, handling risk situations, and developing decision making strategies. At the end of the program the results were similar among families of children with either asthma or epilepsy. Children had improved knowledge, beliefs, attitudes, and behaviors, as well as decreased fears about death and disruption in family life. Parents also reported an increase in knowledge and a decrease in anxiety (Tieffenberg et al., 2000). These families reported an improvement in family dynamics, with lower incidences of school absenteeism and emergency department visits (Tieffenberg et al., 2000). It is important to note that although the researchers had a large sample size (N = 355),

all of the children were Spanish-speaking and only half of them had epilepsy. These factors affect the ability to generalize the study findings.

The three intervention studies discussed above included both parents and children with epilepsy in their samples. Each of the educational interventions was comprised of medical knowledge pertaining to epilepsy and was administered over a designated time period. Each of the studies used different instruments to measure outcome data and none of the studies had significant findings. Although these studies provide potential implications for future research, the psychosocial impacts of childhood epilepsy on the family were not addressed. The literature demonstrates that negative consequences of living with epilepsy are a result of more than seizure type, frequency, and medication side effects. The psychosocial implications also need to be addressed as part of a successful intervention.

Parents of children with epilepsy have a significant impact on their child's quality of life. If parents can successfully manage the stress associated with this chronic condition, they may be able to help their family adapt to living with such an uncertain illness trajectory. If parents can learn how to interpret their child's reactions to stressful situations, and be given information on how to appropriately respond to those reaction behaviors, then the child will be able to cope with difficult situations. Therefore, it is crucial that an intervention provide parents with both information and coping strategies. Creating Opportunities for Parent Empowerment (COPE) is an intervention that teaches parents what behaviors they can expect in their children as a normal response to illness, and how to help their child cope with the illness experience. The COPE intervention has the potential to be successful with parents of children with epilepsy.

Creating Opportunities for Parent Empowerment (COPE)

The COPE intervention was designed to provide mothers with information on how they could affect positive psychological outcomes in their children following discharge from the hospital following an acute episodic illness (Melnyk et al., 1997). The COPE Intervention was comprised of information that taught mothers how to recognize the normal behavioral responses to hospitalization that their children ages 1 to 6 years may experience. This information allowed mothers to predict how their children, ages 1 to 6 years, would behave. Self-regulation supports the idea that anxiety would be decreased in the mother if the intervention helped to increase her ability to understand the situation by teaching her what to expect (Melnyk et al., 1997). It would then be expected that anxiety in the child would also be decreased as the emotional contagion hypothesis supports the idea that the emotions of the parent are transferred to the child (Melnyk et al., 1997).

The COPE intervention therefore teaches mothers how to respond to their children's behavior. According to control theory, providing an intervention that helps mothers understand what their role is in supporting their children during a hospitalization, will increase their confidence (Melnyk et al., 1997). Melnyk et al. (1997) proposed that providing mothers with information would decrease their level of anxiety and increase their confidence in their ability to help their children cope with the experience. Information provided in writing and by audiotape, consisted of two parts and included examples of behavioral changes they could expect in their children as a result of hospitalization, and how to respond to those behaviors (Melnyk, 1994). An initial two-group experimental pilot study was conducted with 30 mothers of children between the ages of 1 and 6 years old with a first time acute episodic illness requiring admission to a pediatric intensive care unit (PICU) in Upstate New York. These children had not

experienced prior hospitalizations. Sixteen mothers received the COPE intervention in two phases, while the remaining 14 mothers comprised the control group and received standard care information in two phases. The initial phase for the experimental group was administered after admission to the unit, and contained information regarding children's expected responses to being in the hospital, and what the mother could do to help her child adjust to the hospital experience (Melnyk et al., 1997).

The second phase of the intervention was administered after the child was transferred from the intensive care unit to the general pediatric unit. During this phase mothers were provided additional information to enhance their understanding of the material provided in the first phase. Mothers were provided a workbook to complete with their children, which included activities to help the child cope with medical procedures both during and after hospitalization. These activities included puppet play, therapeutic medical play, and creating an "I am special" book (Melnyk et al., 1997). The initial phase for mothers in the control group consisted of information about the intensive care unit itself. Phase II for the control group included activities to complete with the child including: coloring, reading, and playing with clay (Melnyk et al., 1997).

Results of this initial pilot study were significant. This study measured several variables of interest including maternal support during procedures, maternal mood state, maternal stress, maternal anxiety, maternal role change, and child behavior (see Table 2 pg. 39) (Melnyk et al., 1997). Mothers who received the COPE intervention provided more support to their children during procedures ($p <$. 05), reported less negative mood state ($p < .10$), and less stress ($p = .05$) twenty-four hours after admission to the intensive care unit when compared to mothers in the control group (Melnyk et al., 1997). Although there was no significant difference in mothers'

anxiety, mood state, or post-traumatic stress disorder symptoms between the two groups following hospitalization, the COPE intervention was found to have a large effect size (*ES* = .80) on anxiety, a medium effect size (*ES* = .46) on mood state and a large effect size (*ES* = .87) on post-traumatic stress disorder symptoms (Melnyk et al., 1997). Following hospital discharge, mothers who participated in the COPE intervention did report less change in their parenting role ($p = <.10$), which also produced a large effect size (*ES* = .90). There were no significant differences in the report of child behaviors between the two groups (Melnyk et al., 1997).

This pilot study utilizing the COPE intervention with mothers of acutely ill children had a significant impact on parenting skills and psychological symptoms in mothers during the time of hospitalization. However, differences between mothers in the intervention group and the control group did not continue past the time of the hospitalization, despite the fact that the COPE intervention did demonstrate a large effect size on anxiety, post-traumatic stress symptoms, and maternal role change (Melnyk et al., 1997). The findings from this study were limited by sample size (*N* = 30) and the inability to collect data from all participants at the designated time periods (Melnyk et al., 1997).

Following the success of this initial pilot study, additional studies utilizing the COPE intervention have been developed for parents of both children in the pediatric intensive care unit and infants in the neonatal intensive care unit (see Table 2 pg. 39). A randomized controlled trial was conducted utilizing the COPE intervention for mothers of children between the ages of 2 and 7 years admitted to a PICU. This study differed from the original pilot in that it included an educational "booster" session at home via telephone two to three days after discharge and follow up assessments occurred up to twelve months after the hospitalization (Melnyk et al., 2004). High attrition rates in both the intervention (n = 44, 50.5%) and control (n = 51, 67%) groups

resulted in low power so effect sizes were also calculated (Melnyk et al., 2004). Medium effect sizes were noted for maternal state anxiety (*ES* = .40), negative mood state (*ES* = .42), and stress (*ES* = .40) one year after hospitalization (Melnyk et al., 2004).

The COPE intervention for mothers of premature infants admitted to a neonatal intensive care unit (NICU) was designed differently than the original COPE intervention for mothers of children admitted to a pediatric intensive care unit. In this study, the educational information was made specific to mothers of premature infants and included recognizing behaviors and developmental cues demonstrated by neonates (Melnyk et al., 2001a). In addition, the educational sessions continued past the time of the hospitalization as the last phase of the COPE intervention was administered in the child's home one week after discharge from the NICU (Melnyk et al., 2001a). Variables and outcome measures for this study are listed in Table 2. This pilot study was limited by small sample size (*N* = 42). As a result, power to detect differences between the intervention and control groups was low so effect sizes were also calculated (Melnyk et al., 2001a). Initially, mothers who participated in the COPE intervention reported less stress related to the NICU environment when compared to mothers in the control group (*p* = .05), but this difference lessened over time and prior to discharge home there was no significant difference between the two groups (Melnyk et al. 2001a). There were small to medium effect sizes related to maternal anxiety (*ES* = .53) and depression (*ES* = .53) during hospitalization, but again these findings were not consistent over the course of the COPE intervention and post hospital discharge effect sizes for both anxiety (*ES* = .19) and depression (*ES* = .19) were small (Melnyk et al., 2001a).

After the pilot, the COPE intervention for parents of infants in the NICU was then conducted as a randomized controlled trial across two institutions (Melnyk et al. 2006). This

study had a large sample size (N = 260) resulting in a power of .80 at the .05 level of significance based on a medium to large effect size (Melnyk et al., 2006). Over time mothers who participated in the COPE intervention demonstrated less state anxiety (p = .05), fewer depressive symptoms (p = .02), less general stress (p = .05), and increased parental beliefs (p < .001). Fathers in the study did not report significant differences in their psychological outcome measures. Fathers who participated in the COPE intervention did demonstrate significant outcomes related to positive infant interactions (p = .003), involvement in physical care (p = .04), and increased parental beliefs (p = .001) (Melnyk et al., 2006).

Although the COPE intervention has demonstrated improved outcomes in both parents and children during an unplanned hospitalization, these positive outcomes have not been sustained over time. In these previous studies the effectiveness of the COPE intervention decreased over time. In the previous studies utilizing the COPE intervention, information is given to parents during the hospitalization and two to three days after hospital discharge. Parents receive the COPE intervention during the stressful hospitalization and this may affect retention of the material. Also, these parents did not necessarily have a need to use the information over time as the majority of children did not have a chronic illness. The COPE intervention has yet to be tried with parents of children with chronic conditions who are hospitalized. Developing the COPE intervention for children with chronic conditions has been identified as an area for future research (Melnyk et al., 2006). For the COPE intervention to be successful with parents of children with chronic conditions, the delivery of the intervention will need to be modified.

Table 2

Prior Intervention Studies Using the COPE Intervention

Researchers & Year	Sample	Measures	Findings
lnyk, Alpert-Gillis, nsel, Cable-Beiling, & Rubenstein 1997	30 mothers of 1-6yo children admitted to PICU with accidental trauma or respiratory infections	Index of Parent Support During Intrusive Procedures (IPS) Index of Parent Participation/Hospitalized Child (IPP) State-Trait Anxiety Inventory (STAI) Profile of Mood States (POMS) Pediatric Stressor Scale: PICU (PSS: PICU) Post-Hospital Stress Index for Parents (PSI-P) Post-Hospital Behavior Questionnaire (PBQ) Post-Hospital Stress Index for Children (PSI-C) Parenting Role Questionnaire (PRQ)	Mothers in the COPE Intervention provided more support to their children during procedures when compared to control group Mothers in the COPE Intervention reported less negative mood state, fewer PTSD symptoms and less stress when compared to control group Mothers in the COPE Intervention reported less parental role change after hospitalization when compared to control group
Melnyk, Alpert-Gillis, Feinstein, Fairbanks, Schultz-Czarniak, Hust, et al. 2001	42 mothers of low birth weight premature infants admitted to NICU	Mental Development Index (MDI) STAI POMS Parental Stressor Scale: NICU (PSS:NICU) Maternal-Infant Interaction Scale (MIIS) Nursing Child Assessment Feeding Scale (NCAFS) Home Observation for Measurement of the Environment (HOME) Parental Beliefs Scale (PBS)	Infants in the COPE Intervention had no developmental delays at 6 months when compared to control group Mothers in the COPE Intervention reported less stress when compared to control group Mothers in the COPE Intervention have more confidence in their ability to parent the infant when compared to control group

Table 2. cont.

Melnyk, Alpert-Gillis, Feinstein, Crean, Johnson, Fairbanks, et al. 2004	163 mothers of 2-7yo children admitted to PICU with respiratory problems, accidental trauma, seizures, infections, ingestions, hematologic, or cardiac problems	STAI POMS PSS: PICU PSI-P Involvement in Physical Care (VAS-PC) Involvement in Emotional Care (VAS-EC) IPP PBS PSI-C Behavioral Assessment System for Children (BASC)	Mothers in the COPE Intervention reported less PTSD symptoms, fewer behavior problems in child, less stress when compared to control group Mothers in the COPE Intervention were more involved in children's physical and emotional care when compared to control group Mothers in the COPE Intervention reported less negative mood states and depression when compared to control group Mothers in the COPE Intervention reported stronger beliefs regarding their ability to enhance child's adjustment when compared to control group
Melnyk, Feinstein, Alpert-Gillis, Fairbanks, Crean, Sinkin, et al. 2006	386 families, including 245 mothers and 145 fathers, of low birth weight premature infants admitted to the NICU	STAI Beck Depression Inventory (BDI) PSS: NICU PBS Index of Parent Behavior – NICU (IPB) Interaction with Infant – NICU (VAS-I) Involvement in Infant Care – NICU (VAS-C) Sensitivity to Needs of Infant – NICU (VAS-S)	Mothers in the COPE Intervention reported less stress, less anxiety, and less depression when compared to control group Mothers and fathers reported higher parental beliefs, more positive parenting interactions when compared to control group Fathers in the COPE Intervention were more involved in infant care when compared to control group

The COPE Intervention for Parents of Children with Epilepsy

For this study, self-regulation was the theoretical framework used to guide the implementation of the intervention. Self-regulation theory is useful in developing interventions aimed at enhancing both emotional and functional coping in parents of children with epilepsy by helping parents understand what is expected to happen during the illness experience (Melnyk, et al., 1997). These interventions will decrease parental stress by helping parents to be able to anticipate the needs of their children.

The COPE intervention has been successful with parents of children who are acutely ill, however, it also has the potential to be successful among parents of children with chronic conditions when they are hospitalized. Children with epilepsy often experience frequent hospitalizations as a result of the unpredictable nature of their condition. The hospital experience has the potential to have long lasting, and negative effects on the child (Vessey, 2003; Melnyk, 2000). Current intervention studies in the literature address the medical management of living with epilepsy, but few attempt to address the psychological and behavior problems that often result. The COPE intervention can be used to address the science gap that currently exists. Young children with epilepsy experience frequent hospitalizations and medical procedures that are a necessary part of treating their condition. However, these frequent and unpredictable interventions have significant consequences. Often, young children experience stress during hospitalization when their parents are uncertain what their role is in supporting their child during this frightening time (Melnyk, 2000). An important nursing role is to facilitate the involvement of the parent in the ongoing acute care of his or her child. This is particularly important when considering how to best prepare young children for the tests and procedures they will undergo when in the hospital. Previous interventions have examined positive or supportive interventions

for preparing children for medical procedures. However, few of these studies considered the experiences of children with chronic conditions who are forced to undergo procedures on a repetitive basis and how that might affect the child's response. Children with epilepsy experience multiple hospitalizations and medical procedures during the course of their lifetime.

Parents of children with epilepsy hospitalized for long term monitoring experience the same challenges associated with not knowing what behaviors to expect from their child as a result of a hospital admission or how to respond appropriately to those behaviors. What is different in this population is the fact that when these children are discharged from the hospital, the child and their parents have to deal with the psychological effects of hospitalization plus the ongoing uncertainty surrounding their chronic condition. It can be hypothesized that these children experience the same behavioral changes, as that of a child with an acute illness, as a result of their hospital experience. However, in addition to the stress associated with hospitalization, children with epilepsy are also dealing with other co-morbidities associated with their condition including, developmental and cognitive delays, and behavior problems. Since the child and family may endure these experiences repeatedly over the course of a lifetime, the COPE intervention will need to be modified to address the chronic nature of living with epilepsy. This chronicity will be reflected by changes in the terminology used in both the audiotaped and written information provided to the parents. The COPE intervention will be administered beginning in the hospital, but phase II and III will take place in the child's home after discharge from the hospital. This change in delivery of the educational materials is important since the family lives and deals with epilepsy on a day-to-day basis that does not end once the child returns home. This study will serve to fill the gap that exists in the literature by determining the efficacy of the modified version of the COPE intervention with parents of children with chronic

conditions such as epilepsy. Additional studies using the COPE intervention will follow to continue to address the needs of children with chronic conditions and their families.

Summary

The psychosocial implications associated with parenting a child with epilepsy have the potential to significantly influence coping of the child as well as the ability of the family to function. Historically, the focus has been on increasing knowledge about epilepsy. However, this education reviews seizure types, seizure precautions, and medications, but seldom includes information pertaining to how to support the child and facilitate ongoing adjustment to the chronic nature of an unpredictable condition. The COPE intervention has the potential to address these concerns. The following chapter will discuss the methods used for implementing the COPE intervention among this population.

CHAPTER III

Introduction

This chapter provides an overview of the design, sample and setting of the current intervention. Also presented in this chapter are the study procedures and data collection instruments including psychometric properties. An overview of the modified COPE intervention is discussed followed by a discussion of the data analyses. Finally, the protection of human subjects is presented.

Research Design

This clinical study uses a randomized controlled trial to test the efficacy of the COPE Intervention for parents of children with epilepsy. This intervention was administered at three intervals: 1) during hospital admission in writing and by audiotape, MP3 download or Podcast, 2) three days following hospital discharge by telephone, and 3) four to six weeks after hospital discharge in writing and by audiotape, MP3 download or Podcast.

The following (see Figure 2) outlines the overall study timeline.

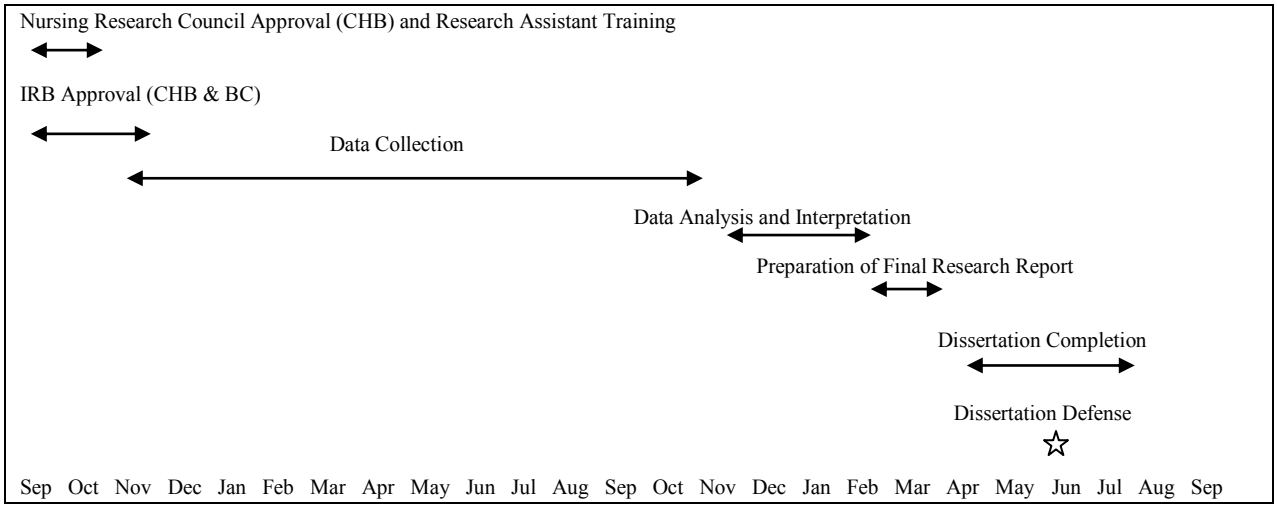

Figure 2. Study Timeline

Study Sample and Setting

The setting for this study was an inpatient neuroscience unit at Boston Children's Hospital, which is renowned for its clinical excellence in the care and management of children with epilepsy. This unit has eight beds designated for long term electroencephalogram (EEG) monitoring for children who have intractable epilepsy. Children are admitted for long term EEG monitoring to further characterize their seizures, often after medication failure. This hospitalization is particularly stressful to parents since there is no way to know if the information gathered during the admission will be useful and will result in better seizure control. In addition, this hospitalization may result in the diagnosis of intractable epilepsy as parents are told their child is not a candidate for surgical resection of their seizure focus. Parents often hold on to the hope that surgery will make their child seizure free and the news that they are not can be devastating for the family.

An admission for long term EEG monitoring lasts approximately one week and information is gathered to determine how the medical team can best optimize seizure control. Testing done during this time includes; magnetic resonance imaging (MRI), positron emission tomography (PET), and single-photon emission computerized tomography (SPECT) scans. The results of the admission may result in a change in medication, a special diet, or brain surgery to remove an area of the brain that is producing the seizure activity. All of these results, good or bad, produce additional anxiety for the families involved. This population was chosen for this study because the COPE Intervention has the potential to be extremely useful in these situations by teaching

parents skills to manage this constant uncertainty in their daily lives and facilitate coping in their child.

Participants were parents who met the following inclusion criteria. 1) Parents of children who were 2 to 6 years old and had been diagnosed with epilepsy for a minimum period of six months. This criterion was established because a diagnosis of epilepsy for six months met one criterion for living with a chronic condition (National Institutes of Health, 2007). 2) Parents of children admitted to an inpatient neuroscience unit for long term EEG monitoring. This criterion was established because these children had seizure disorders that were not easily controlled by medication and therefore necessitated an inpatient hospital admission. This met the second criterion for a chronic condition; the need for ongoing monitoring, treatment, or adaptation in activities of daily living (National Institutes of Health, 2007). 3) Parents who had a high school education and were literate in English at a ninth grade reading level. This criterion was necessary to ensure that the parents were able to understand the COPE intervention related information and to complete measurement instruments. 4) Parents had access to a cellular or home telephone. This criterion was established as phase II of the COPE intervention required the ability to receive a follow up telephone call from a nurse after the child was discharged from the hospital. 5) Parents who were healthy and had no significant co-morbid conditions. This criterion was established to ensure that parents would be able to successfully participate in the COPE intervention and facilitate coping in their child.

Subject exclusion criteria included: 1) parents of children who had been diagnosed with co-morbid conditions including, but not limited to; significant

developmental delays, cancer, and mitochondrial or metabolic disorders. These children with significant cognitive developmental delays were excluded as they were unable to participate in the activities required as part of the research intervention. Also, certain co-morbid conditions could potentially alter the course of the child's future independent of the effects of epilepsy.

Study Procedure

The research team consisted of the principal investigator, clinical nurse specialist for neuroscience programs, a staff nurse, and two graduate nursing students who also worked as staff nurses on the inpatient unit where the study took place. Prior to any interaction with potential research subjects, each member of the team was trained by the principal investigator. Training consisted of reviewing the protocol in depth, including inclusion criteria and the consenting process. Team members were also educated on the data collection instruments, including how to complete and score each measure. The information provided to parents as part of the COPE intervention was reviewed with each team member. Only one person was responsible for the follow up phone calls so that the information provided would be standardized.

Each day a member of the research team would monitor the census of the inpatient neuroscience unit to identify potential study subjects. If participants met inclusion criteria, a member of the research team would give the parents or legal guardians a letter introducing the study within twenty-four hours after admission to the unit. A member of the research team would then follow up with the family within twenty-four hours to ask if they were interested in participating. If parents expressed interest, the study was explained in further detail and any questions they had were answered by a member of the research team. If the parent agreed,

informed consent then was obtained by a member of the research team or principal investigator. Parents who did not wish to be enrolled in the study were thanked for their time, and reassured that the care of their child would not be affected by their decision.

On enrollment, subjects were randomly assigned to either the intervention or control group using a random numbers table. After group assignment, participants followed the timeline in Table 3.

Table 3

Intervention Timeline

	Intervention Group	Usual Care Group
During admission to the unit	• Signed informed consent • Completed questionnaires (including demographic information) • Received information about the hospital unit and information in phase I of the COPE Intervention	• Signed informed consent • Completed questionnaires (including demographic information) • Received information about the hospital unit
Three days after discharge from hospital	• Received telephone call to review information given in the hospital during phase I of the COPE Intervention	• Received telephone call to review satisfaction with hospital admission and discharge
One week after discharge from hospital	• Completed questionnaires at home	• Completed questionnaires at home
Four to six weeks after discharge	• Received phase III information at home	• Received coloring book at home
Four to six weeks after phase III of the intervention	• Completed questionnaires at home	• Completed questionnaires at home

Within twenty-four hours after signing informed consent, all parents were asked to complete the Parental Belief Scale (PBS), Beck Depression Inventory-II (BDI-II), State-Trait Anxiety Inventory (STAI-Y) and Behavior Assessment System for Children 2-Parent Report Scale (BASC2-PRS). These instruments took approximately 30 to 45 minutes to complete in total. Parents were given the option of having a hospital volunteer stay with or play with their

child during this time. Phase I of the intervention was then administered prior to the child's discharge from the hospital by a member of the research team. Phase II and phase III of the intervention were then administered at the family's home three days and four to six weeks respectively after the child was discharged from the hospital.

Phase II and III of the COPE intervention were administered at home, therefore, extra measures were taken to ensure the fidelity of the administration of the intervention. The telephone call in phase II of the intervention was administered by only one member of the research team. This team member was trained by the principal investigator and provided with a telephone script. This ensured that each parent received the same information during phase II. Phase III was conducted by the principal investigator only. Again, this ensured that all participants received the same standard intervention. Included with the information in phase III was a short satisfaction survey for the parent to complete and return to the principal investigator. This survey promoted fidelity by documenting that participants received and participated in the parent-child activities that were required in phase III of the intervention.

Four to six weeks after phase III of the intervention, parents were again asked to complete the same four data collection instruments at home. Parents' involvement in this study required a commitment of a maximum of twelve weeks.

The COPE Intervention

The timing of the administration of the COPE intervention (see Appendix B) was modified to be implemented with parents of children with epilepsy. Families of children with epilepsy need to learn how to adapt to the stress associated with living with an uncertain prognosis and repeat hospitalizations, procedures, and appointments. The role of the parent to facilitate coping in their child with epilepsy does not end with the hospitalization. Instead, these

concepts need be continually reinforced on an ongoing basis and each time the child is faced with additional hospitalizations or procedures. The COPE intervention has the potential to be useful among this chronically ill population because it teaches parents how to recognize and interpret their child's behavioral cues. Young children may not be able to verbally express their worries or concerns; rather it is manifested in their behavior. Once parents recognize these behaviors, they can use their cognitive schema to formulate a plan on how to help their child cope with the experience. Parents can then use developmentally appropriate coping strategies that they have found to be successful in the past. The anticipated outcome with the COPE intervention is that parental ability to improve their child's adaptation to living with a chronic condition by anticipating problems and intervening before the child manifests significant disruptive behaviors. The aim of the COPE intervention for parents of children with epilepsy is to provide information regarding how to respond to their child's behavioral cues and in return, to support the child's behavioral and emotional adjustment to living with his or her chronic condition.

Although the information presented in the COPE intervention was appropriate for this population, the timing of the COPE intervention was modified for this study. Families of children with epilepsy live with the ramifications of a chronic condition that continues to have a daily impact on their lives after they are discharged from the hospital. For this reason, it was important to continue to provide parents with the tools to implement the principals of the COPE intervention in the home setting. Therefore, the administration of the COPE intervention was divided into three phases the first to be initiated during the hospitalization and the second and third phase to continue after the child was discharged home.

Phase I of the COPE intervention began within twenty-four hours of study enrollment and included oral and digitally recorded information regarding children's expected responses to illness, and how caregivers could facilitate the child's adjustment to the experiences associated with the hospitalization. This information was reinforced throughout the hospitalization. During this phase, parents were encouraged to participate in the care of their child by learning techniques to help prepare the child for medical procedures. Parents were informed about developmentally normal responses to a hospitalization or medical procedures for children in this age group. Examples of which included; being uncooperative or showing signs of regression such as thumb sucking or being incontinent. Parents were instructed to deal with these issues by being present for the child and never punitive. Parents were instructed to always inform their child when a separation was necessary and emphasize when they would return. Throughout this phase, parents were encouraged to ask questions about treatment plans or anything that concerned them. They were encouraged to deal with their own anxiety by seeking support away from the child's bedside as it is potentially very anxiety-provoking for the child to witness a parent who is out of control (Melnyk & Alpert-Gillis, 1998).

Phase II of the COPE intervention consisted of a telephone call from a member of the research team three days after discharge from the hospital to reinforce information provided during phase I of the program. The information was designed to help parents anticipate and respond to behavior changes that occurred when the child returned to his or her home environment. After hospitalizations for diagnostic workups or condition treatment, children may regress, lose confidence in their ability to perform new tasks, and be more afraid of being alone. If parents were able to recognize these symptoms as normal, they could help the child adapt over time. Parents were instructed to continually reassure the child, to establish daily routines for the

child, and to encourage the child to try new things. Parents were also told that it was important to continue with their parenting routines and to set limits on behaviors (Melnyk & Alpert-Gillis, 1998).

Phase III of the COPE intervention included a parent-child activity workbook designed to teach parents how to use therapeutic play techniques to help the child cope with medical procedures and hospitalizations. Parents read "Jenny's Wish" with their children to facilitate dialogue about events and feelings that occurred during the hospitalization. Parents were then instructed on how to use medical and puppet play to help the child express his or her feelings, and decrease any fear associated with the experience (Melnyk et al., 1997). The puppets and props as well as instructions and short scenarios were sent home with each family to facilitate the activity. The frequency with which parents used these techniques was at their own discretion. Ideally, the purpose of providing the parents with these tools was so the techniques would be available for them to use not only at this time, but also following future hospitalizations and medical events.

Usual Care Group. The Usual Care Group received standard nursing care and education regarding medication management and seizure first aid. In addition they received information, oral and written, that discussed tests to be administered during the hospitalization. This education was provided by the staff nurses on the inpatient neuroscience unit and occurred throughout the hospitalization. Standard education sheets pertaining to medications and diagnostic studies were developed by nurse experts on this inpatient neuroscience unit and approved by the hospital. It is standard practice for staff nurses on the unit to provide these educational handouts to parents prior to discharge home. The Usual Care Group also received a phone call within one week after discharge from a nurse who asked questions related to the

hospital experience, and if they had any further needs or questions. Lastly, the Usual Care Group received a coloring book about being in the hospital four to six weeks after hospital discharge.

Instruments

The following measurement instruments were used throughout this study to collect data; the Parental Beliefs Scale, the Beck Depression Inventory II, the State-Trait Anxiety Inventory, and the Behavior Assessment System for Children-2. These instruments were chosen, in consultation with Dr. Melnyk, because they were designed to measure the constructs of interest in this study and had been used in previous research utilizing the COPE intervention. This would additionally allow for replication of results. Each instrument demonstrated reliability and validity in a variety of research studies with children with chronic conditions. These measurement instruments have been used in previous research studies using the COPE intervention (Melnyk et al., 2001a; Melnyk et al., 2001b ; Melnyk et al., 1997; Melnyk, 1994). Table 4 outlines the variables measured with each instrument as well as how the instrument is scored. The remainder of the chapter will discuss the reliability and validity of each instrument.

Table 4

Data Collection Measures

Variable	Measure	Reading level	Scoring	Time to Complete
Decreased Parent Belief	Parental Beliefs Scale (PBS)	5th grade	Score range 20-100 Higher score indicates positive beliefs	5 minutes
Depression	Beck Depression Inventory II (BDI-II)	5th grade	Score range 0-63 Higher score indicates more severe depression	10-20 minutes
Anxiety	State-Trait Anxiety Inventory (STAI)	6th grade	Score range 20-80 Higher score indicates greater level of anxiety	10 minutes
Child Behavioral Problems	Behavior Assessment System for Children (BASC2-PRS)	3rd grade	Higher scores indicate greater levels of the problem behavior being measured	10-20 minutes

Parental Beliefs Scale. (See Appendix B). This scale was developed by Melnyk (1994) to better characterize the extent to which child behavior and parental role confusion results in anxiety of the parent. The items that comprise the scale were derived from an extensive review of the literature pertaining to parenting a hospitalized child. Content validity for this scale was obtained by asking eight pediatric clinical nurse specialists and a group of mothers to review all scale items (Melnyk, 1994). The scale was then used with a total of 273 subjects across three intervention studies that involved parenting hospitalized children (Melnyk, 1994). The scale consists of 20 items divided into two subscales. The total scale scores range from 20 to 100 with a Cronbach's alpha of .86 for the total score. The first subscale consists of eight items that measure parent's beliefs about their hospitalized child. The second subscale consists of 12 items that address the parent's belief about their role during the hospitalization (Melnyk, 1994). Items are scored using a five point Likert scale, which ranges from "strongly agree" to "strongly

disagree." The first subscale has a total score of eight to 40 with a Cronbach's alpha of .76. The second scale has a total score of 12 to 60 with Cronbach's alpha of .84. For each of these scales a higher score indicates positive beliefs. In two follow up studies, Melnyk et al., (2007; 2004) further demonstrated reliability of the parental beliefs scale among mothers of hospitalized critically ill children. The Cronbach's alpha for the overall score in both of these additional studies was 0.91 (Melnyk et al., 2007; 2004).

Beck Depression Inventory II (BDI-II). (See Appendix B). Beck et al. (1996) developed the BDI-II as an instrument to identify the presence or severity of depressive symptoms as outlined in the *Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV).* The BDI-II is a revised version of the original scale where items were developed based on the symptom descriptions of psychiatric outpatients (Beck et al., 1996). The BDI-II is a 21 item self-report scale, which can be administered in a written or oral form in approximately 10-20 minutes. Each item is scored on a scale of 0-3 resulting in a total possible score ranging from 0-63. A higher score indicates more severe depression. Specific scores are as follows: 0–9 indicates minimal depression, 10–18 indicates mild depression, 19–29 indicates moderate depression and 30–63 indicates severe depression. Initial psychometric testing was done with a population of 500 psychiatric outpatients and 120 college students. Cronbach's alpha for the two groups was 0.92 and 0.93 respectively. Test-retest reliability was conducted with 26 outpatients resulting in a correlation of 0.93 (Beck et al., 1996). Horowitz et al. (2001) used the BDI-II in their study of maternal depression and infant responsiveness that resulted in Cronbach's alphas ranging from 0.87 to 0.89. This measure also has demonstrated content validity and reliability among several populations including parents of children with cancer (Sahler et al., 2005) and parents of children with cystic fibrosis (Glasscoe, Lancaster, Smyth, &

Hill, 2007). Leung and Slep (2006) used the BDI-II to examine the association between parental depression and how the parent disciplines the child and found that depressed parents were more likely to perceive misbehavior in their child.

State-Trait Anxiety Inventory (STAI-Y). (See Appendix B). Spielberger (1983) developed STAI-P to measure state and trait anxiety levels. This measure consists of two self-report scales. The first scale, measuring state anxiety, consists of 20 items related to the level of anxiety at the present time. The second scale, measuring trait anxiety, consists of 20 items that indicate proneness to anxiety. Each scale has a possible score ranging from 20 to 80 and high scores indicate a greater level of anxiety. Initial psychometric properties for the scale were tested using a population of college students for test-retest intervals. Cronbach's alphas for the state scale ranged from 0.86-0.95, and 0.89-0.91, for the trait scale. Test-retest resulted in correlations ranging from 0.16-0.62 for the state scale, and 0.73-0.86 for the trait scale (Spielberger, 1983). Melnyk et al. (1997) used the STAI-P to test the COPE Intervention with parents of children experiencing unplanned hospitalizations and reported a Cronbach's alpha of 0.92 for the trait scale, and 0.95 for the state scale. This measure also has demonstrated content validity and reliability (Cronbach's alpha 0.93) among parents of children with brain injury, cancer, and anxiety (Wade, Carey, & Wolfe, 2006; Cobham, Dadds, & Spence, 1998; Grootenhuis & Last, 1997).

Behavior Assessment System for Children-Parent Report Scale (BASC2-PRS). (See Appendix B). Reynolds and Kamphaus (1992) originally developed BASC2-PRS to help parents identify behavior problems in their children. The instrument has been revised and the current 2nd edition (BASC-2) consists of 134-160 items depending on the age of the child. Parents of children between the ages of 2 years and 5 years will

complete 134 items, which are comprised of both adaptive and clinical scales. Adaptive scales include items related to activities of daily living, adaptability, functional communication, and social skills. Clinical scales include items related to aggression, anxiety, attention, atypicality, depression, hyperactivity, somatization, and withdrawal. For children between the ages of 6 years and 11 years, there are an additional 26 items. These additional items include conduct problems (clinical scale) and leadership (adaptive scale). Cronbach's alphas range from 0.74 to 0.80 based on a normative sample drawn from classrooms, community mental health centers, residential schools, and juvenile detention centers (Flanagan, 1995). This measure has demonstrated reliability among parents of children with attention deficit hyperactivity disorder (Harvey, Danforth, Ulaszek, & Eberhardt, 2001), cancer (Moore et al., 2003), HIV (Bachanas et al., 2001), and unplanned hospitalization (Melnyk et al., 2004).

Analytic Plan

The full description of the final analytic plan used in this study is located in the following chapter. The minimum proposed sample size was 70, with 35 in the intervention group, and 35 in the control group (assumes *ES* = 0.35, power = 0.80, alpha = 0.05 for ANCOVA) (Sample power, 2007). The effect size used to calculate the sample size was based on previous intervention research with the COPE intervention. Effect size reported in the previous studies ranged from .01 to .89 (Melnyk et al., 2006; Melnyk et al., 2001a). Based on the wide range of effect sizes, a medium effect size was chosen for this study. Because this study was three months in duration and some subject attrition was likely, the plan was to include an over-sampling of 25% (Melnyk et al., 2004), resulting in a total sample size of 88 parents, 44 per group. The inpatient neuroscience unit at Boston Children's Hospital admits over 700 children

each year for the management of epilepsy, therefore, obtaining a sample from this pool to meet the requirements for the study proposed appeared to have been more than adequate.

Protection of Human Subjects

This study involved human subjects and approval was obtained from the Internal Review Boards at Boston College and Boston Children's Hospital. In addition to the principal investigator, members of the research team included four nurses who worked on the inpatient neuroscience unit including; the clinical nurse specialist, one staff nurse and two graduate nursing students. All members of the research team obtained certification for "The Protection of Human Research Subjects" by using the online training to complete the "Social / Behavioral Researchers Who Interact with Research Subjects" module provided through the Collaborative Institutional Training Initiative (CITI).

The protection of human subjects was achieved in this study by carefully obtaining informed consent from each subject. Informed consent ensured that adequate steps were taken so the subject was able to make a free, rational and informed decision regarding whether or not to enroll in this particular study. The principal investigator or trained member of the research team obtained informed consent. The consent process included information regarding; subject status, study goals, type of data, procedures, nature of the commitment, sponsorship, subject selection, potential risks, potential benefits, alternatives, compensation, confidentiality pledge, voluntary consent, right to withdraw and withhold information, and contact information (Polit & Beck, 2004). Subjects were made aware that any information indicating risk to the parent or safety of the child would not be kept confidential and would be reported to the appropriate person including the unit social worker. The consent information was presented to the subject both orally and in writing at the time of recruitment into the study. Subjects were told that on

enrollment into the study, they would be randomly assigned to either the control group and receive usual care, or the intervention group, which would receive the COPE intervention in addition to usual care. The consent was written at a 5th grade reading level so subjects were able to understand the material (see Appendix C). The subjects signed the consent form and were given a photocopy for their records. The original signed consent form was kept on file with the principal investigator in a locked cabinet located on the inpatient neuroscience unit, which was only accessible to the principal investigator. Each subject was informed, both orally and in writing (see Appendix C), of the option of removing themselves from the study at any time and without penalty.

CHAPTER IV

Introduction

This chapter will present recruitment and retention issues of participants in the current study. As data collection was implemented, problems with both recruitment and retention became apparent. The target enrollment for the study was 88 subjects and by the end of year one, only 24 subjects had been enrolled. There were an additional 73 subjects who were screened during the first year, but were ineligible as they did not satisfy the inclusion requirements. As a result, the recruitment and retention strategies were modified and additional research questions and hypotheses were developed based on the limited sample size. These issues and corrective actions are detailed below. Lastly, the modified hypotheses and detailed analytic plan will be presented.

Recruitment Issues

Potential subjects for inclusion in the COPE intervention were initially identified for eligibility using a weekly list of elective admissions for long term EEG monitoring on the inpatient neuroscience unit at Boston Children's Hospital. The inpatient neuroscience unit admits over 700 patients each year for the management of epilepsy. To participate in the COPE intervention, parents were required to perform certain activities with their children. As noted in the description of the COPE intervention in Chapter 2 and part of the original inclusion criteria, children needed to be able to participate in the program from a developmental standpoint. It was necessary that the child be able to communicate with his or her parents so that they could assess the effect of the intervention from a behavioral perspective. Unfortunately, the majority (n = 139/243) of potential subjects were excluded based on the developmental level of the child with epilepsy. Children with epilepsy have a high incidence of several co-morbid conditions,

including cognitive and developmental delays (Daniel, Russell, & Thomas, 2008; Aldeklamp & Arends, 2004; Bailet & Turk, 2000).

Although children with epilepsy are at an increased risk for additional behavioral and cognitive co-morbidities, with over 700 children admitted annually to the inpatient neuroscience unit at Boston Children's Hospital, obtaining a sample of 88 participants was a reasonable expectation. Unfortunately, at the time the study began economic pressures including, changes in insurance coverage altered the population being admitted to the hospital for monitoring. Children who were medically stable were no longer approved for what was considered an elective admission. As a result, ambulatory electroencephalogram monitoring replaced inpatient monitoring. Therefore, school-age children who were developmentally capable of being monitored at home were no longer admitted to the hospital. This had a dramatic effect on the inpatient population eligible for this study. There did continue to be several eligible participants and recruitment procedures continued as outlined below.

Shortly after their admission to the inpatient unit, those families whose children met inclusion criteria were given a letter (see Appendix B) introducing the study. Attached to this introductory letter was an opt-in card to express their wish to learn more about the study. This method was employed as a way to support the idea that parents were choosing to participate in the study without coercion. This is a common passive recruitment strategy (Kao et al., 2011). Parents were asked to return the card to the nurse, which indicated their permission to be contacted by the principal investigator. This method was very difficult to track and very few cards were returned. The bedside staff nurse was responsible for collecting the card from the parents but often they were too busy or forgot to do so. The parent was also given instructions on how to return the card, but these parents are asked to stay at their child's bedside, so this

additional inconvenience interfered with the success of the initial recruitment plan. Another identified concern was that this approach did not help families fully understand the study. Parents who do not have a good understanding of the potential benefits of a research study are unlikely to consent to participate (Newberry et al., 2010; Bruzzese, Gallagher, McCann-Doyle, Reiss & Wjetunga, 2009; Baquet, Henderson, Commiskey & Morrow, 2008).

It was recognized that having a child who is hospitalized is often financially burdensome for families. Parents often stay in the hospital several days to weeks to remain at their child's bedside. Families incur costs associated with meals, parking, and lost wages. These non-medical out-of-pocket expenses are not covered by health insurance and can be quite burdensome resulting in additional stress for the family (DiFazio & Vessey, 2011). Asking parents to participate in a research study places additional burdens on an already stressful situation. Although there was no direct cost to the family for participating in the study, they were asked for their time.

Modifications in Recruitment Strategies

In order to help improve the enrollment rate, the population from which subjects were recruited was expanded. Due to the higher than expected presence of significant developmental delay among this population of children with epilepsy, the inclusion criteria were modified to include children between the ages of 2 and 6 years with a variety of both acute and chronic neurological conditions. Although the initial aim of the study focused on the chronic nature of epilepsy, the literature suggests it is the uncertainty related to the unpredictable nature of the condition that contributes to the stress reaction in parents that results in subsequent behavior problems in the child (Mu, 2005; Mu et al., 2001). This uncertainty is present in a variety of pediatric neurological conditions because the prognosis is often unknown and the disease course

unpredictable (Mah, Thannhauser, McNeil & Dewey, 2008; Hodell, 2004). The revised inclusion criteria were as follows: 1) parents of children who were 2 to 6 years old and had been diagnosed with an acute or chronic neurological condition, 2) parents of children admitted to an inpatient neuroscience unit, 3) parents who had a high school education and were literate in English at a ninth grade reading level, necessary to understand the COPE intervention related information and to complete measurement instruments, and 4) parents who had access to a cellular or home telephone as phase II of the COPE intervention. The original exclusion criterion was not modified. The revised inclusion criteria were reviewed and approved by the Institutional Review Boards at both Boston College and Boston Children's Hospital (see Appendix A).

The next modification included introducing the study using face-to-face interaction instead of the opt-in cards. This was accomplished, in part, by adding additional members to the research team. Expanding the research team allowed for a more robust recruitment strategy. First, this allowed for broader coverage of time periods including evenings and weekends thus enabling more people to be approached about being in the study. The research team members were able to provide more explanations about the study and parents questions and/or concerns could be immediately addressed. Research team members were knowledgeable about the study as well as the patient population, permitting them to build a trusting relationship with the family; this strategy is known to positively improve enrollment and participation (Kao et al., 2011). Parents are unlikely to consent to being part of a research study if they do not believe that the research team is concerned about their or their child's best interest. Establishing a relationship with potential subjects is one way to foster the feeling of trust among participants (Patel, Doku, & Tennakoon, 2003). In this study the additional research team members were all registered

nurses who worked on the unit from which subjects were being recruited. These nurses were able to establish a rapport with these families and were trained to understand the study protocol and were therefore able to explain the importance of the project. This plan addressed the concern that parents who do not have a good understanding of the potential benefits of a research study are unlikely to consent to participate (Newberry et al., 2010; Bruzzese et al., 2009; Baquet et al., 2008).

To help alleviate some of the burden associated with the hospitalization, parents were offered remuneration for their time of participation in the study. Parents were asked to complete three sets of questionnaires during the duration of the study. After each completed set of questionnaires was returned, the parent received a $25 Visa gift card.

It is interesting to note that some researchers have found varying degrees of recruitment success when using incentives. Karlson and Rapoff (2008) demonstrated that whether or not an incentive was offered to research subjects made no significant difference on who enrolled in and completed the study. However, Ely, Coleman and Kotzer (2007) noted that mothers of children with sickle cell disease valued small incentives that were provided to them for their participation in research. Chang, Hendricks, Slawsky, and Locastro (2004) conducted a behavioral intervention for patients with congestive heart failure and those subjects reported the number one reason for deciding to consent to the study was benefit to self, including monetary compensation. It is interesting to note the differing opinions regarding incentives among research participants. Families caring for chronically ill children may be experiencing additional financial burden, which would likely make the incentive more appealing for them.

After instituting these specific recruitment strategies, the rate of recruitment improved significantly. At the termination of subject recruitment, a total of 46 subjects were enrolled in

the study. However, although recruitment was improved, the attrition rate was high and many subjects did not continue to phase II and III of the study. Issues with ongoing retention were then identified and addressed.

Retention Issues

Each subject's involvement took place over a three-month period. The original proposed sample size included an oversampling of 20% based on the attrition rates of previous studies using the COPE intervention. Karlson and Rapoff (2008) found that in research studies involving families of children with chronic conditions, attrition rate in the follow up period after the intervention was as high as 32%. Parents in that study cited many reasons for their inability to continue with the study. These reasons included; being too busy, having no interest in the project, feeling that the intervention was not necessary, and having to balance the demands associated with too many medical appointments (Karlson & Rapoff, 2008). Parents of children with neurological conditions face many of the same demands. In this study some parents did express disinterest in the study stating that they did not believe the information being presented was applicable to their child. Other parents expressed interest in this study, but did not have the time to complete the data collection instruments once they were home after being discharged from the hospital.

Revised Retention Strategies

Several strategies were implemented to help decrease the rate of attrition. It has been reported that increased time between contacts with subjects often results in an increased rate of attrition (Karlson & Rapoff, 2008). When conducting a longitudinal study it is necessary to keep the subjects engaged in the process. This study was challenging because it required parents to complete questionnaires on their own at home and mail them back to the principal investigator.

These families have demanding daily schedules and remembering to complete the questionnaires was a daunting task. In order to maintain contact between study phases, the decision was made to send additional e-mail or letter reminders to families. The additional reminder was reviewed and approved by the Institutional Review Boards at both Boston College and Boston Children's Hospital (see Appendix A). If the questionnaires were still not returned, a second reminder was sent. Cotter, Burke, Stouthamer-Loeber and Loeber (2005) found that it often took several attempts to contact a research subject in a longitudinal study. The average number of contact attempts ranged from three to seven before they were able to successfully reach a subject. In this study we did attempt to contact each subject a minimum of three times via phone, e-mail, or letter. Again, realizing the additional burden participating in a research study places on parents; parents were offered a $25 Visa gift card each time they returned completed questionnaires.

Research Questions

Despite the changes in recruitment and retention strategies, attrition rate continued to be high. The participant sample continued to decrease over the course of the study so that there were significantly fewer participants who completed phase III of the study when compared to the number of participants who completed phase I. As a result, the sample size was not adequate to conduct the data analysis as previously described in Chapter 3. Rather than simply determining if the COPE intervention made a significant impact, the original research questions and hypotheses were modified to examine if there were any changes at any of the three time points throughout the study. Also, additional research questions were developed prior to data analysis based on the experiences from the current study. These questions addressed possible reasons for the high attrition rate.

Finally, research questions were again developed prior to data analysis to determine what impact the psychological state of the parent had on their decision to participate in the study as well as the potential relationship to their child's behavior. Although the number of fathers who participated in the study was small, the decision was made to analyze their results separate from mothers. This decision was based on the fact that there is a scant amount of literature that exists describing the experience of fathers caring for children with chronic conditions. Therefore, any information learned from this study had potential implications for future research.

The following research questions were analyzed:

RQ1a. Is there a statistically significant difference in parent confidence in their parenting skills between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

RQ1b. Is there a statistically significant difference in parent depressive symptoms between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

RQ1c. Is there a statistically significant difference in parental anxiety between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

RQ1d. Is there a statistically significant difference between behavior assessment system scores (externalizing, internalizing, behavioral, and adaptive) by group (usual care versus intervention) and by time (pre-intervention versus one week post)?

RQ2a. Which of the demographic variables, if any, predict one-week or eight-week program completion?

RQ2b. Do mothers' anxiety and depression scores predict one-week or eight-week program completion?

RQ2c. Do fathers' anxiety and depression scores predict one-week or eight-week program completion?

RQ3. At pretest, is there a statistically significant difference in children's behavior problems (externalizing, internalizing, behavioral, and adaptive) by parent (mother versus father)?

RQ4. At pretest, do mothers' scores on the anxiety and depression scales predict children's behavior problems (externalizing, internalizing, behavioral, and adaptive)?

RQ5. At pretest, do father's scores on the anxiety and depression scales predict children's behavior problems (externalizing, internalizing, behavioral, and adaptive)?

Date Analysis Plan

A variety of data analysis methods were utilized to answer the questions raised by the additional research questions.

Research Question 1

RQ1a. Is there a statistically significant difference in parent confidence in their parenting skills between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

To examine research question 1a, three one-between-one-within analyses of variance (ANOVAs) were conducted to assess if there is a difference in parent confidence in their parenting skills between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention). The dependent variable, parent confidence in parenting skills, was measured with the *Parental Beliefs Scale* at three time periods.

RQ1b. Is there a statistically significant difference in parent depressive symptoms between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

To examine research question 1b, three one-between-one-within analyses of variance (ANOVAs) were conducted to assess if there is a difference in parent depressive symptoms between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention). The dependent variable, parent depressive symptoms, will be measured with the *Beck Depression Inventory-II (BDI-II)* at three time periods.

RQ1c. Is there a statistically significant difference in parental anxiety between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

To examine research question 1c, three one-between one-within multivariate analyses of variance (MANOVAs) were conducted to determine if there are statistically significant differences in parental anxiety between each of the three time periods (pre-intervention versus

one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention). The dependent variable, parental anxiety, has two levels (state and trait). This was measured with the *State-Trait Anxiety Scale* at three time periods.

RQ1d. Is there a statistically significant difference between behavior assessment system scores (externalizing, internalizing, behavioral, and adaptive) by group (usual care versus intervention) and by time (pre-intervention versus one week post)?

To examine research question 1d, a one-between, one-within multivariate analysis of variance (MANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test for equality of variance was not significant for any score, verifying the assumption of equality of variance. Normality was assessed with eight Kolmogorov Smirnov tests, which were significant for one score (internalizing) at pre-intervention.

Research Question 2

RQ2a. Which of the demographic variables, if any, predict one-week or eight-week program completion?

To examine research question 2a, two binary logistic regressions were conducted to assess if the participant demographics (parent's gender, parent's age, child's age, race, marital status, parent's education, and parents income) predicted the completion of program at one week (wave two) or eight weeks (wave three).

RQ2b. Do mothers' anxiety and depression scores predict one-week or eight-week program completion?

To examine research question 2b, two binary logistic regressions were conducted to assess mothers' anxiety and depression scores in the scores in the prediction of program completion at one week (wave two) or eight weeks (wave three).

RQ2c. Do fathers' anxiety and depression scores predict one-week or eight-week program completion?

To examine research question 2c, two binary logistic regressions were conducted to assess fathers' anxiety and depression scores in the prediction of program completion at one week (wave two) or eight weeks (wave three).

Research Question 3

RQ3. At pretest, is there a statistically significant difference in children's behavior problems (externalizing, internalizing, behavioral, and adaptive) by parent (mother versus father)?

To examine research question 3, a multivariate analysis of variance (MANOVA) was conducted to assess if there were simultaneous differences on *Behavior Assessment System* scores (externalized, internalized, behavioral, and adaptive) by parent gender (male versus female).

Research Question 4

RQ4. At pretest, do mothers' scores on the anxiety and depression scales predict children's behavior problems (externalizing, internalizing, behavioral, and adaptive)?

In order to examine research question 4, four multiple linear regressions were conducted to assess if mothers' anxiety (state and trait) and depression scores predict the four behavior assessment system scores (externalizing, internalizing, behavioral, and adaptive) for mothers.

Research Question 5

RQ5. At pretest, do father's scores on the anxiety and depression scales predict children's behavior problems (externalizing, internalizing, behavioral, and adaptive)?

In order to examine research question 5, four multiple linear regressions were conducted to assess if fathers' anxiety (state and trait) and depression score predict the four behavior assessment system scores (externalizing, internalizing, behavioral, and adaptive).

The following chapter will discuss the results of the data analysis in detail.

CHAPTER V

Results

The current study investigated the preliminary efficacy of the COPE intervention with parents of children with chronic neurological conditions. The study enrolled a total of 46 parents whose children were admitted to the inpatient neuroscience unit at Boston Children's Hospital. The sample included a comparison of two groups (usual care versus intervention). There were 24 (52.2%) parents in the Usual Care Group and 22 (47.8%) parents in the group that received the COPE Intervention.

Research Sample Description

The Usual Care Group was comprised by a majority of female parents (*n* = 19, 79.2%), who were White-Caucasian (*n* = 20, 83.3%), and married (*n* = 18, 75%). A large number were aged 40-49 (*n* = 10, 41.7%) and had a high school diploma (*n* = 10, 41.7%). The report of yearly household income varied, with 10 (41.7%) reporting an income more than $100,000, five (20.8%) reporting an income between $75,000 and $100,000 and four (16.7%) reporting an income less than $25,000. The Intervention Group was comprised of a majority of female parents (*n*=18, 81.8%), who were White-Caucasian (*n*=18, 81.8%) and married (*n*=15, 68.2%). A large number were aged 30-39 (*n*=10, 45.5%) and had a high school diploma (*n*=7, 31.8%). The report of yearly household income varied, with seven (33.3%) reporting an income less than $25,000 (*n* = 7, 33.3%), five (23.8%) reporting more than $100,000 and four (19%) reporting an income between $75,000 and $100,000. Frequencies and percentages of parent demographic characteristics are presented for the usual care and intervention groups in Table 5.

Table 5

Parent Demographic Characteristics by Group (Usual Care and Intervention)

	Usual Care Group		Intervention Group	
Parent Characteristic	*n*	%	*n*	%
Gender				
Female	19	79.2	18	81.8
Male	5	20.8	4	18.2
Age				
18 to 29	5	20.8	5	22.7
30 to 39	9	37.5	10	45.5
40 to 49	10	41.7	7	31.8
Ethnicity				
White/Caucasian	20	83.3	18	81.8
Black/African American	1	4.2	1	4.5
Latino/Hispanic	3	12.5	3	13.6
Marital Status				
Single	2	8.3	4	18.2
Divorced	2	8.3	1	4.5
Living with partner	2	8.3	2	9.1
Married	18	75.0	15	68.2
Highest Degree Completed				
Less than high school	0	0.0	1	4.5
High School	10	41.7	7	31.8
Two-year college	2	8.3	5	22.7
Bachelor's degree	8	33.3	4	18.2
Master's degree	4	16.7	3	13.6
PhD or higher	0	0.0	2	9.1
Yearly Household Income				
Less than 25,000	4	16.7	7	33.3
25,000 to 50,000	3	12.5	2	9.5
50,000 to 75,000	2	8.3	3	14.3
75,000 to 100,000	5	20.8	4	19.0
More than 100,000	10	41.7	5	23.8

Frequencies and percentages were calculated on the demographic characteristics of the participants' children who were admitted to the inpatient neuroscience unit. The Usual Care Group was comprised of 13 (54.2%) male children and 11 (45.8%) female children between the ages of two and six (M = 4.00, SD = 1.44). Twenty-two (91.7%) of the children had a current diagnosis of seizures, and two (8.3%) children had a neurosurgical condition and did not experience seizures. For 13 (54.2%) children this was *not* a new diagnosis and for 11 (45.8%) children it was *new*. For those children with a seizure diagnosis, the type of seizures varied, with the largest number of children (n = 7, 33.3%) experiencing absence seizure with staring spells. The frequency of seizure was daily (n = 11, 50%) or weekly (n = 7, 31.8%) for the majority of these children. The number of medications varied with a range of none to more than three, and the majority of children were currently taking at least one medication (n=19, 79%).

The Intervention Group was comprised of seven (31.8%) male children and 15 (68.2%) female children between the ages of two and six (M = 3.81, SD = 1.47). Thirteen (59.1%) of the children had a current diagnosis of seizures, and seven (31.8%) children in the intervention group had a neurological diagnosis other than seizures. The diagnoses other than seizures included the following; brain tumors, encephalitis, opsoclonus-myoclonus syndrome, neurofibromatosis, and pseudotumor cerebri. For 13 (59.1%) children this was *not* a new diagnosis and for nine (40.9%) children it was *new*. Among the children experiencing seizures, seizure type varied, with the largest number of children experiencing complex partial seizures (n = 6, 50%) or absence seizures with staring spells (n = 4, 33.3%). The frequency of seizure was daily (n = 5, 38.5%) or weekly (n = 4, 30.8%) for the majority of these children. The number of medications varied with a range of none to more than three, and the majority of children were currently taking at least one medication (n = 8, 36%), but five (38.5%) were not taking any medications. Frequencies and

percentages of child demographic characteristics are presented for the usual care and intervention groups in Table 6.

Table 6

Child Demographic Characteristics by Group (Usual Care and Intervention)

	Usual Care Group		Intervention Group	
Child Characteristic	*n*	*%*	*n*	*%*
Gender				
Female	11	45.8	15	68.2
Male	13	54.2	7	31.8
Age				
Two	5	20.8	5	22.7
Three	4	16.7	6	27.3
Four	6	25.0	3	13.6
Five	4	16.7	4	18.2
Six	5	20.8	4	18.2
Race				
White/Caucasian	20	83.3	18	81.8
Black/African American	1	4.2	1	4.5
Latino/Hispanic	3	12.5	3	13.6
Current Diagnosis				
Seizure Disorder	22	91.7	13	59.1
Type of Seizures				
Absence	7	33.3	4	33.3
Atonic	1	4.8	0	0.0
Generalized	4	19.0	1	8.3
Simple partial	4	19.0	1	8.3
Complex partial	4	19.0	6	50.0
Other	1	4.8	0	0.0
No diagnosis at this time	0	0.0	2	9.1
Other	2	8.3	7	31.8
New Diagnosis				
Yes	11	45.8	9	40.9
No	13	54.2	13	59.1

Table 6 cont.

	Usual Care Group		Intervention Group	
Child Characteristic	*n*	%	*n*	%
Seizure Frequency				
Daily	11	50.0	5	38.5
Weekly	7	31.8	4	30.8
Monthly	1	4.5	2	15.4
Every few months	2	9.1	1	7.7
A few times a year	1	4.5	0	0.0
Less than once a year	0	0.0	1	7.7
Current Medications (number)				
None	3	13.6	5	38.5
One	4	18.2	3	23.1
Two	5	22.7	4	30.8
Three	5	22.7	0	0.0
More than three	5	22.7	1	7.7

Data Collection

As described in Chapter 3, (see Table 3), data collection was conducted in three phases. At each phase the parent participants were asked to complete a series of questionnaires. The pretest was administered upon enrollment (phase I); the first follow-up assessment was completed after one week of the intervention (phase II) and the final assessment was completed eight weeks after the intervention (phase III). Twenty-two (47%) participants completed all three phases of data collection, this included 11 (45.8%) who received usual care and 11 (50%) who received the COPE intervention. Frequencies and percentages on the number of participants, who completed phase I, phase I and II and all three phases are presented for the Usual Care and Intervention Groups in Table 7.

Table 7

Frequencies and Percentages on Number of Participants who Completed Phase One, Two, Three by Group (Usual Care and Intervention)

	Usual Care (*N* = 24)		Intervention (*N* = 22)	
Phase completed	*N*	*%*	*n*	*%*
Phase one only	10	41.7	6	27.3
Phase one and two only	3	12.5	5	22.7
Completed all three phases	11	45.8	11	50.0

Research Question 1a. Is there a statistically significant difference in parent confidence in their parenting skills between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

Pre-Intervention versus One-Week Posttest. In order to examine the difference in parent confidence in their parenting skills by group (usual care versus intervention) and by time (pre-intervention versus one-week posttest), a one-between, one-within analysis of variance (ANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test of equality of variance was not significant (F (1, 28) = 0.11, p = .739, and F (1, 28) = 0.22, p = .640 for pre and one-week post), verifying the assumption of equality of variance. Normality was assessed with a Kolmogorov Smirnov test, which was not significant (p = .986 and .916 for pre and one-week post), verifying the assumption of normality.

The main effect of time was not significant, F (1, 28) = 3.01, p = .094, indicating that there was no difference in the mean parent confidence in parenting skills scores by time. The main effect of group was not significant, F (1, 28) = 0.19, p = .669, indicating that there was no

difference between the mean parent confidence in parenting skills scores by group (usual care versus intervention). Lastly the effect of the interaction was not significant, F (1, 28) = 3.38, p = .077, indicating that the interaction of time and group did not significantly impact the mean parent confidence in parenting skills scores. Results of the one-between, one-within ANOVA are presented in Table 8. Means and standard deviations of the mean parent confidence in parenting skills scores are presented by group and time in Table 9.

Table 8

One-Between, One-Within ANOVA for Parental Beliefs Scale Scores by Time (Pre-Intervention versus One- Week Posttest) and Group (Usual Care and Intervention)

Source	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects							
Group	1	30.67	30.67	0.19	.669	0.01	0.07
Error	28	4612.68	164.74				
Within-Subjects							
Time	1	152.15	152.15	3.01	.094	0.10	0.39
Time*Group	1	170.55	170.55	3.38	.077	0.11	0.43
Error	28	1414.93	50.53				

Table 9

Means and Standard Deviations for Parental Beliefs Scale Scores by Time (Pre-Intervention versus One- Week Posttest) and Group (Usual Care and Intervention)

		M	*SD*	*N*	*Min*	*Max*
Parental Beliefs Scale (pretest)	Usual care	71.43	10.00	14	53	98
	Intervention	73.38	10.97	16	52	89
	Total	72.47	10.39	30	52	98
Parental Beliefs Scale (one week post)	Usual care	78.00	9.96	14	58	96
	Intervention	73.19	10.44	16	59	91
	Total	75.43	10.34	30	58	96

Pre-Intervention versus Eight Week Posttest. In order to examine the difference in parent confidence in their parenting skills by group (usual care versus intervention) and by time (pre-intervention versus eight- week posttest), a one-between, one-within analysis of variance (ANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test of equality of variance was not significant (F (1, 20) = 2.83, p = .108, and F (1, 20) = 1.95, p = .177 for pre and one-week post), verifying the assumption of equality of variance. Normality was assessed with two Kolmogorov Smirnov tests, which were not significant (p = .986 and .090 for pre and eight-week post), verifying the assumption of normality.

The main effect of time was not significant, F (1, 20) = 0.01, p = .937, indicating that there was there was no difference in the mean parent confidence in parenting skills scores by time. The main effect of group was also not significant, F (1, 20) = 2.31, p = .144, indicating that there was no difference in the mean parent confidence in parenting skills scores by group.

Lastly the effect of the interaction was not significant, F (1, 20) = 0.37, p = .549, indicating that the interaction of time and group did not significantly impact the mean parent confidence in parenting skills scores. Results of the one-between, one-within ANOVA are presented in Table 10. Means and standard deviations of by group and time are presented in Table 11.

Table 10

One-Between, One-Within ANOVA for Parent Belief Scale Score by Time (Pre-Intervention versus Eight Weeks Posttest) and Group (Usual Care and Intervention)

Source	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects							
Group	1	439.11	439.11	2.31	.144	0.10	0.30
Error	20	3806	190.31				
Within-Subjects							
Time	1	1.84	1.84	0.01	.937	0.00	0.05
Time*Group	1	108.21	108.21	0.37	.549	0.02	0.09
Error	20	5838.46	291.92				

Table 11

Means and Standard Deviations for Parental Beliefs Scale Scores by Time (Pre-Intervention versus Eight Weeks Posttest) and Group (Usual Care and Intervention)

		M	*SD*	*N*	*Min*	*Max*
Parental Beliefs Scale (Pretest)	Usual care	72.36	10.42	11	53	98
	Intervention	75.55	6.07	11	52	89
	Total	73.95	8.48	22	52	98
Parental Beliefs Scale (8 week)	Usual care	69.64	27.01	11	-8	91
	Intervention	79.09	9.46	11	64	100
	Total	74.36	20.33	22	-8	100

One Week Posttest versus Eight Week Posttest. In order to examine the difference in parent confidence in their parenting skills by group (usual care versus intervention) and time (One week posttest versus Eight week posttest), a one-between, one-within analysis of variance (ANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test of equality of variance was not significant (p = .236 and p = .177 for one-week post and eight-week post), verifying the assumption of equality of variance. Normality was assessed with two Kolmogorov Smirnov tests, which were not significant (p = .916 and .090 for one-week post and eight-week post), verifying the assumption of normality.

The main effect of time was not significant, F (1, 20) = 0.03, p = .862, indicating that there was no difference in mean parent confidence in parenting skills scores by time. The main effect of group was also not significant, F (1, 20) = 0.08, p = .781, indicating that there was no difference in mean parent confidence in parenting skills scores by group. Lastly the effect of the

interaction was not significant, F (1, 20) = 2.75, p = .113, indicating that the interaction of time and group did not significantly impact the mean parent confidence in parenting skills scores. Results of the one-between, one-within ANOVA are presented in Table 12. Means and standard deviations of mean parent confidence in parenting skills scores by group and time are presented in Table 13.

Table 12

One-Between, One-Within ANOVA for Parent Belief Scale Score by Time (One Week Posttest versus Eight Week Posttest) and Group (Usual Care and Intervention)

Source	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects							
Group	1	19.11	19.11	0.08	.781	0.00	0.06
Error	20	4805.55	240.28				
Within-Subjects							
Time	1	8.21	8.21	0.03	.862	0.00	0.05
Time*Group	1	728.21	728.21	2.75	.113	0.12	0.35
Error	20	5306.09	265.31				

Table 13

Means and Standard Deviations for Parental Beliefs Scale Scores by Time (One Week Posttest versus Eight Week Posttest) and Group (Usual Care and Intervention)

		M	*SD*	*N*	*Min*	*Max*
Parental Beliefs Scale (one week)	Usual care	78.64	8.72	11	58	96
	Intervention	71.82	10.78	11	59	91
	Total	75.23	10.18	22	58	96
Parental Beliefs Scale (8 week)	Usual care	69.64	27.01	11	-8	91
	Intervention	79.09	9.46	11	64	100
	Total	74.36	20.33	22	-8	100

Research Question 1b. Is there a statistically significant difference in parent depressive symptoms between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

Pre-Intervention versus One-Week Posttest. In order to examine the difference in parent depressive symptoms by group (usual care versus intervention) and by time (pre versus one week post), a one-between, one-within analysis of variance (ANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test of equality of variance was not significant (p = .356 and .301), verifying the assumption of equality of variance. Normality was assessed with two Kolmogorov Smirnov tests, which were not significant (p = .380 and .384), verifying the assumption of normality.

The main effect of time was not significant, F (1, 28) = 3.38, p = .077, indicating that parent depressive symptoms were not significantly different by time. The main effect of group

was not significant, F (1, 28) = 0.26, p = .615, indicating that parent depressive symptoms were not significantly different by group. The interaction was significant, F (1, 28) = 7.88, p = .009, indicating that the interaction between time and group had a significant impact on parent depressive symptoms. Results of the one-between, one-within ANOVA are presented in Table 14. Means and standard deviations of parent depressive symptoms by group and time are presented in Table 15.

Table 14

One-Between, One-Within ANOVA for BDI Score by Time (Pre-Intervention versus One Week Posttest) and Group (Usual Care and Intervention)

Source	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects							
Group	1	26.79	26.79	0.26	.615	0.01	0.08
Error	28	2905.21	103.76				
Within-Subjects							
Time	1	84.23	84.23	3.38	.077	0.11	0.43
Time*Group	1	196.23	196.23	7.88	.009	0.22	0.77
Error	28	697.50	24.91				

Table 15

Means and Standard Deviations for BDI Scores by Time (Pre-Intervention versus One Week Posttest) and Group (Usual Care and Intervention)

		M	*SD*	*N*	*Min*	*Max*
BDI (Pretest)	Usual care	11.29	6.73	14	0	33
	Intervention	9.00	8.80	16	-8	25
	Total	10.07	7.86	30	-8	33
BDI (one week)	Usual care	5.29	6.53	14	-8	17
	Intervention	10.25	9.30	16	0	34
	Total	7.93	8.38	30	-8	34

To assess the differences in parent depressive symptoms specifically post hoc analyses were conducted using paired sample *t* tests and independent sample *t* tests. There was a significant difference among participants in the Usual Care Group, the parent depressive scores, as measured by the BDI-II, at pre-intervention ($M = 11.29$, $SD = 6.73$) were significantly larger than the parent depressive symptoms at one-week posttest ($M = 5.29$, $SD = 6.53$). Results for the post hoc analyses are presented in Table 16.

Table 16

Post Hoc Analyses for BDI Scores by Time (Pre-Intervention versus One Week Posttest) and Group (Usual Care and Intervention)

Post hoc analysis	*t*	*Df*	*p*	95% CI for Mean Difference
Dependent sample t test on BDI scores for each group by time				
Usual care by time	3.53	13	.004	[2.33, 9.67]
Intervention by time	-0.66	15	.521	[-5.31, 2.81]
Independent sample t test on BDI scores for each time period by group				
Pretest	0.14	44	.887	[-4.46, 5.14]
One week Posttest	-1.67	28	.106	[-11.06, 1.13]

Pre-Intervention versus Eight Week Posttest. In order to examine the difference in parent depressive symptoms by group (usual care versus intervention) and by time (pre-intervention versus eight week posttest), a one-between, one-within analysis of variance (ANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test of equality of variance was not significant (p = .380 and .384), verifying the assumption of equality of variance. Normality was assessed with two Kolmogorov Smirnov tests, which were not significant (p = .636 and .465), verifying the assumption of normality.

The main effect of time was not significant, F (1, 20) = 0.60, p = .448, indicating that parent depressive symptoms were not significantly different by time. The main effect of group was not significant, F (1, 20) = 0.12, p = .731, indicating that parent depressive symptoms were not significantly different by group. The effect of interaction was not significant, F (1, 20) = 1.31, p = .266, indicating that the interaction between time and group did not have a significant

impact on parent depressive symptoms. Results of the one-between, one-within ANOVA are presented in Table 17. Means and standard deviations of parent depressive symptoms by group and time are presented in Table 18.

Table 17

One-Between, One-Within ANOVA for BDI Score by Time (Pre-Intervention versus Eight Week Posttest) and Group (Usual Care and Intervention)

Source	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects							
Group	1	23.27	23.27	0.12	.731	0.01	0.06
Error	20	3817.27	190.86				
Within-Subjects							
Time	1	40.09	40.09	0.60	.448	0.03	0.11
Time*Group	1	87.36	87.36	1.31	.266	0.06	0.19
Error	20	1336.55	66.83				

Table 18

Means and Standard Deviations for BDI Scores by Time (Pre-Intervention versus Eight Week Posttest) and Group (Usual Care and Intervention)

		M	*SD*	*N*	*Min*	*Max*
BDI (Pretest)	Usual care	10.82	7.01	11	0	33
	Intervention	9.45	9.45	11	-8	25
	Total	10.14	8.15	22	-8	33
BDI (8 week)	Usual care	6.09	8.95	11	-8	22
	Intervention	10.36	17.23	11	-8	57
	Total	8.23	13.58	22	-8	57

One Week Posttest versus Eight Week Posttest. In order to examine the difference in parent depressive symptoms by group (usual care versus intervention) and by time (one week posttest versus 8 week posttest), a one-between, one-within analysis of variance (ANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test of equality of variance was not significant (p = .498 and p = .384), verifying the assumption of equality of variance. Normality was assessed with two Kolmogorov Smirnov tests, which were not significant (p = .612 and p = .465), verifying the assumption of normality.

The main effect of time was not significant, F (1, 20) = 0.10, p = .752, indicating that parent depressive symptoms were not significantly different by time. The main effect of group was not significant, F (1,20) = 1.55, p=.228, indicating that parent depressive symptoms were not significantly different by time. The effect of interaction was not significant, F (1, 20) = 0.64, p = .432, indicating that the interaction between time and group did not have a significant impact

on parent depressive symptoms. Results of the one-between, one-within ANOVA are presented in Table 19. Means and standard deviations of parent depressive symptoms by group and time are presented in Table 20.

Table 19

One-Between, One-Within ANOVA for BDI Score by Time (One Week Posttest versus Eight Week Posttest) and Group (Usual Care and Intervention)

Source	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects							
Group	1	349.46	349.46	1.55	.228	0.07	0.22
Error	20	4513.46	225.67				
Within-Subjects							
Time	1	3.27	3.27	0.10	.752	0.01	0.06
Time*Group	1	20.46	20.46	0.64	.432	0.03	0.12
Error	20	637.27	31.86				

Table 20

Means and Standard Deviations for BDI Scores by Time (One Week Posttest versus Eight Week Posttest) and Group (Usual Care and Intervention)

		M	*SD*	*N*	*Min*	*Max*
BDI (one week)	Usual care	4.18	6.46	11	-8	17
	Intervention	11.18	9.82	11	0	34
	Total	7.68	8.87	22	-8	34
BDI (8 week)	Usual care	6.09	8.95	11	-8	22
	Intervention	10.36	17.23	11	-8	57
	Total	8.23	13.58	22	-8	57

Research Question 1c. Is there a statistically significant difference in parental anxiety between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

Pre-Intervention versus one week Post. In order to assess if there were statistically significant differences between anxiety inventory scores (state and trait) by group (usual care versus intervention) and by time (pre-intervention versus one week post), a one-between, one-within multivariate analysis of variance (MANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test for equality of variance was not significant for any score (p = .706, .554, .190, .971 for state pre, state one week post, trait pre, and trait one week post respectively), verifying the assumption of equality of variance. Normality was assessed with 4 Kolmogorov Smirnov tests (p = .975, .421,

.915, .668 for state pre, state one week post, trait pre, and trait one week post respectively), which all were not significant, verifying the assumption of normality.

The main effect of time was significant, F (2, 27) = 9.20, p = .001, indicating simultaneous differences existed on state and trait inventory scores by time. Further analysis revealed that the effect of time for state anxiety inventory scores was significant, F (1, 28) = 10.39, p = .003, indicating that the state anxiety inventory score at pre-intervention (M = 41.50, SD = 11.00) was significantly larger than the anxiety inventory score at one week posttest (M = 36.00, SD = 8.93). The effect of time for trait anxiety inventory scores was not significant, F (1, 28) = 0.73, p = .401, indicating that the trait anxiety inventory score was not significantly different by time.

The main effect of group was not significant, F (2, 27) = 1.50, p = .241, indicating that simultaneous differences did not exist on state and trait inventory scores by group. The effect of the interaction was not significant, F (2, 27) = 1.59, p = .222, indicating that simultaneous differences did not exist in the interaction of time and group. The individual ANOVAs are presented in Table 21. The means and standard deviations for state and trait anxiety inventory scores by group and time are presented in Table 22.

Table 21

Individual ANOVAs on State and Trait Inventory Scale Score by Group and Time (Pre-Intervention versus One Week Post)

Source	Measure	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects								
Group	State	1	347.14	347.14	2.28	.142	0.08	0.31
	Trait	1	8.70	8.70	0.04	.840	0.00	0.05
Error	State	28	4267.61	152.42				
	Trait	28	5852.65	209.02				
Within-Subjects								
Time	State	1	440.08	440.08	10.39	.003	0.27	0.88
	Trait	1	11.79	11.79	0.73	.401	0.03	0.13
Time*Group	State	1	17.14	17.17	0.41	.530	0.01	0.09
	Trait	1	20.59	20.59	1.27	.269	0.04	0.19
Error	State	28	1185.61	42.34				
	Trait	28	452.90	16.18				

Table 22

Means and Standard Deviations for State and Trait Anxiety Inventory Scores by Group and Time (Pre-Intervention versus One Week Post)

Anxiety Inventory	Group	*M*	*SD*	*N*	*Min*	*Max*
State (Pretest)	Usual care	38.36	10.02	14	21	61
	Intervention	44.25	11.38	16	22	62
	Total	41.50	11.00	30	21	62
State (one week)	Usual care	34.00	8.95	14	21	47
	Intervention	37.75	8.81	16	21	59
	Total	36.00	8.93	30	21	59
Trait (Pretest)	Usual care	35.29	9.09	14	20	61
	Intervention	34.88	10.52	16	22	57
	Total	35.07	9.71	30	20	61
Trait (one week)	Usual care	35.00	11.79	14	21	67
	Intervention	36.94	10.84	16	22	67
	Total	36.03	11.14	30	21	67

Pre-Intervention versus Eight Week Posttest. In order to assess if there were statistically significant differences between anxiety inventory scores (state and trait) by group (usual care versus intervention) and by time (pre-intervention versus eight weeks post), a one-between, one-within multivariate analysis of variance (MANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test for equality of variance was not significant for any score (p = .422, .817, .157, .879 for state pre, state eight week post, trait pre, and trait eight week post respectively), verifying the assumption of equality of variance. Normality was assessed with 4 Kolmogorov Smirnov tests, which all

were not significant (p = .975, .421, .915, .668 for state pre, state eight week post, trait pre, and trait eight week post respectively), verifying the assumption of normality.

The main effect of time was significant, F (2, 19) = 5.23, p = .016, indicating simultaneous differences existed on state and trait inventory scores by time. Further analysis revealed that the effect of time for state anxiety inventory scores was significant, F (1, 20) = 9.86, p = .005, indicating that the state anxiety inventory score at pre-intervention (M = 42.32, SD = 10.97) was significantly larger than the anxiety inventory score at eight week posttest (M = 34.50, SD = 10.95). The main effect of group was not significant, F (2, 19) = 0.72, p = .501, indicating that simultaneous differences did not exist on state and trait inventory scores by group. The effect of the interaction was not significant, F (2, 19) = 1.23, p = .315, indicating that simultaneous differences did not exist in the interaction of time and group. The individual ANOVAs are presented in Table 23. The means and standard deviations for state and trait anxiety inventory scores by group and time are presented in Table 24.

Table 23

Individual ANOVAs on State and Trait Inventory Scale Score by Group and Time (Pre-Intervention versus Eight Week Post)

Source	Measure	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects								
Group	State	1	176.00	176.00	1.06	.317	0.05	0.17
	Trait	1	13.09	13.09	0.06	.810	0.00	0.06
Error	State	20	3337.64	166.88				
	Trait	20	4398.09	219.91				
Within-Subjects								
Time	State	1	67236	67236	9.86	.005	0.33	0.85
	Trait	1	17.82	17.82	0.56	.465	0.03	0.11
Time*Group	State	1	168.09	168.09	2.46	.132	0.11	0.32
	Trait	1	9.09	9.09	0.28	.600	0.01	0.08
Error	State	20	1364.55	68.23				
	Trait	20	642.09	32.11				

Table 24

Means and Standard Deviations for State and Trait Anxiety Inventory Scores by Group and Time (Pre-Intervention versus Eight Week Post)

Anxiety Inventory	Group	*M*	*SD*	*N*	*Min*	*Max*
State (Pretest)	Usual care	38.36	9.30	11	21	61
	Intervention	46.27	11.48	11	22	62
	Total	42.32	10.97	22	21	61
State (8 week)	Usual care	34.45	10.29	11	20	55
	Intervention	34.55	12.09	11	20	63
	Total	34.50	10.95	22	20	63
Trait (Pretest)	Usual care	35.27	9.73	11	20	61
	Intervention	37.27	11.47	11	22	57
	Total	36.27	10.43	22	20	61
Trait (8 week)	Usual care	34.91	11.00	11	20	54
	Intervention	35.09	12.53	11	20	67
	Total	35.00	11.50	22	20	67

One Week Posttest versus Eight Week Posttest. In order to assess if there were statistically significant differences between anxiety inventory scores (state and trait) by group (usual care versus intervention) and by time (one week post versus eight weeks post), a one-between, one-within multivariate analysis of variance (MANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test for equality of variance was not significant for any score (p = .455, .817, .785, .879 for state one week post, state eight week post, trait one week post, and trait eight week post respectively), verifying the assumption of equality of variance. Normality was assessed with

four Kolmogorov Smirnov tests (p = .915, .668, .726, .805 for state one week post, state eight week post, trait one week post, and trait eight week post respectively), which all were not significant, verifying the assumption of normality.

The main effect of time was not significant, F (2, 19) = 1.33, p = .287, indicating simultaneous differences did not exist on state and trait inventory scores by time. The main effect of group was not significant, F (2, 19) = 0.25, p = .778, indicating that simultaneous differences did not exist on state and trait inventory scores by group. The effect of the interaction was not significant, F (2, 19) = 0.91, p = .418, indicating that simultaneous differences did not occur from the interaction of time and group. The individual ANOVAs are presented in Table 25. The means and standard deviations for state and trait anxiety inventory scores by group and time are presented in Table 26.

Table 25

Individual ANOVAs on State and Trait Inventory Scale Score by Group and Time (One Week Post versus Eight Week Post)

Source	Measure	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects								
Group	State	1	68.75	68.75	0.41	.527	0.02	0.09
	Trait	1	32.82	32.82	0.12	.733	0.01	0.06
Error	State	20	3321.91	166.10				
	Trait	20	5480.36	274.02				
Within-Subjects								
Time	State	1	63.84	63.84	1.74	.202	0.08	0.24
	Trait	1	56.82	56.82	2.52	.128	0.11	0.33
Time*Group	State	1	63.84	63.84	1.74	.202	0.08	0.24
	Trait	1	26.27	26.27	1.17	.293	0.06	0.18
Error	State	20	732.82	36.64				
	Trait	20	450.91	22.55				

Table 26

Means and Standard Deviations for State and Trait Anxiety Inventory Scores by Group and Time (One Week Post versus One Week Post)

Anxiety Inventory	Group	*M*	*SD*	*N*	*Min*	*Max*
State (one week)	Usual care	34.45	9.31	11	21	47
	Intervention	39.36	8.18	11	21	59
	Total	36.91	8.91	22	21	59
State (eight weeks)	Usual care	34.45	10.29	11	20	55
	Intervention	34.55	12.09	11	20	63
	Total	34.50	10.95	22	20	63
Trait (one week)	Usual care	35.64	13.25	11	21	67
	Intervention	37.27	11.47	11	22	67
	Total	36.27	10.43	22	21	67
Trait (eight weeks)	Usual care	34.91	11.00	11	20	54
	Intervention	35.09	12.53	11	20	67
	Total	35.00	11.50	22	20	67

Research Question 1d. Is there a statistically significant difference between behavior assessment system scores (externalizing, internalizing, behavioral, and adaptive) by group (usual care versus intervention) and by time (pre-intervention versus one week post)?

Pre-Intervention versus One-Week Posttest. In order to assess if there were statistically significant differences between behavior assessment system scores (externalizing, internalizing, behavioral, and adaptive) by group (usual care versus intervention) and by time (pre-intervention versus one week post), a one-between, one-within multivariate analysis of variance (MANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality

were assessed. The Levene's test for equality of variance was not significant for any score, verifying the assumption of equality of variance. Normality was assessed with eight Kolmogorov Smirnov tests, which were significant for one score (internalizing) at pre-intervention.

The main effect of time was not significant, F (4, 24) = 1.68, p = .187, indicating simultaneous differences did not exist on behavior assessment system scores by time. The main effect of group was not significant, F (4, 24) = 0.99, p = .431, indicating that simultaneous differences did not exist in behavior assessment system scores by group. The effect of the interaction was significant, F (4, 24) = 3.69, p = .018, indicating that simultaneous differences did occur from the interaction of time and group. Further analysis was conducted to examine the effects of the interaction. Only internalized behavior assessment system score was significant, F (1, 27) = 4.79, p = .037, indicating that differences did occur from the interaction of time and group for internalized behavior assessment system scores. Post hoc analyses for internalized behavior assessment system scores revealed no differences by time and group. The individual ANOVAs are presented in Table 27. The means and standard deviations for state and trait anxiety inventory scores by group and time are presented in Table 28. Post hoc analyses for internalized behavior assessment system scores are presented in Table 29.

Table 27

Individual ANOVAs on Behavior assessment System Scores by Group and Time (Pre-Intervention versus One Week Post)

Source	Measure	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects								
Group	Externalized	1	210.61	210.61	0.66	.423	0.02	0.12
	Internalized	1	21.99	21.99	0.05	.820	0.00	0.06
	Behavioral	1	48.38	48.38	0.10	.750	0.00	0.06
	Adaptive	1	177.90	177.90	0.63	.434	0.02	0.12
Error	Externalized	27	8583.49	317.91				
	Internalized	27	11282.08	417.86				
	Behavioral	27	12656.96	468.78				
	Adaptive	27	7629.37	282.57				
Within-Subjects								
Time	Externalized	1	27.89	27.89	0.48	.497	0.02	0.10
	Internalized	1	41.20	41.20	1.05	.314	0.04	0.17
	Behavioral	1	0.00	0.00	0.00	.998	0.00	0.05
	Adaptive	1	47.00	47.00	1.00	.327	0.04	0.16
Time*Group	Externalized	1	49.40	49.40	0.84	.367	0.03	0.14
	Internalized	1	187.75	187.75	4.79	.037	0.15	0.56
	Behavioral	1	163.86	163.86	3.42	.075	0.11	0.43
	Adaptive	1	3.55	3.55	0.08	.786	0.00	0.06
Error	Externalized	27	1585.12	58.71				
	Internalized	27	1058.18	39.19				
	Behavioral	27	1293.41	47.90				
	Adaptive	27	1271.10	47.08				

Table 28

Means and Standard Deviations for Behavior assessment System Scores by Group and Time (Pre-Intervention versus One Week Post)

Behavior assessment System	Group	Pretest		One week post	
		M	*SD*	*M*	*SD*
Externalized	Usual care	53.00	9.81	52.54	12.66
	Intervention	47.31	18.64	50.56	11.20
	Total	49.86	15.35	51.45	11.70
Internalized	Usual care	52.54	12.66	50.69	11.56
	Intervention	50.56	11.20	48.31	20.22
	Total	51.45	11.70	49.38	16.67
Behavioral	Usual care	50.69	11.56	48.77	11.87
	Intervention	48.31	20.22	53.62	13.93
	Total	49.38	16.67	51.45	13.05
Adaptive	Usual care	48.77	11.87	57.15	12.18
	Intervention	53.62	13.93	51.94	21.12
	Total	51.45	13.05	54.28	17.59

Table 29

Post Hoc Analyses for Internalized Behavior assessment System Scores by Time (Pre-Intervention versus One Week Post) and Group

		t	*df*	*p*	95% CI for Mean Difference
Dependent sample t test on internalized BASC scores for each group by time					
Usual care by time		1.15	12	.274	[-1.73, 5.58]
Intervention by time		-2.01	15	.063	[-10.95, 0.32]
Independent sample t test on internalized BASC scores for each time by group					
Pretest		-0.67	42	.507	[-13.98,7.01]
One week Posttest		-1.00	28	.326	[-14.31, 4.92]

Pre-Intervention versus Eight Week Posttest. In order to assess if there were statistically significant differences between behavior assessment system scores (externalizing, internalizing, behavioral, and adaptive) by group (usual care versus intervention) and by time (pre-intervention versus eight weeks post), a one-between, one-within multivariate analysis of variance (MANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test for equality of variance was not significant for any score, verifying the assumption of equality of variance. Normality was assessed with eight Kolmogorov Smirnov tests, which were significant for one score (internalizing) at pre-intervention.

The main effect of time was not significant, F (4, 16) = 0.79, p = .551, indicating simultaneous differences did not exist on behavior assessment system scores by time. The main effect of group was not significant, F (4, 16) = 1.25, p = .329, indicating that simultaneous differences did not exist behavior assessment system scores by group. The effect of the

interaction was not significant, F (4, 16) = 2.86, p = .058, indicating that simultaneous differences did not occur from the interaction of time and group. The individual ANOVAs are presented in Table 30. The means and standard deviations for state and trait anxiety inventory scores by group and time are presented in Table 31.

Table 30

Individual ANOVAs on Behavior assessment System Scores by Group and Time (Pre-Intervention versus Eight Week Post)

Source	Measure	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects								
Group	Externalized	1	48.63	48.63	0.12	.730	0.01	0.06
	Internalized	1	233.66	233.66	0.41	.529	0.02	0.09
	Behavioral	1	0.36	0.36	0.00	.983	0.00	0.05
	Adaptive	1	1036.22	1036.22	4.83	.041	0.20	0.55
Error	Externalized	19	7518.66	395.72				
	Internalized	19	10802.81	568.57				
	Behavioral	19	14699.54	773.66				
	Adaptive	19	4078.26	214.65				
Within-Subjects								
Time	Externalized	1	67.88	67.88	0.98	.334	0.05	0.16
	Internalized	1	38.36	38.36	0.71	.411	0.04	0.13
	Behavioral	1	15.43	15.43	0.49	.493	0.03	0.10
	Adaptive	1	186.40	186.40	2.91	.104	0.13	0.37
Time*Group	Externalized	1	216.45	216.45	3.13	.093	0.14	0.39
	Internalized	1	242.75	242.75	4.46	.048	0.19	0.52
	Behavioral	1	64.76	64.76	2.05	.169	0.10	0.27
	Adaptive	1	3.55	3.55	0.06	.816	0.00	0.06
Error	Externalized	19	1312.46	69.08				
	Internalized	19	1033.54	54.40				
	Behavioral	19	601.14	31.64				
	Adaptive	19	1216.07	64.00				

Table 31

Means and Standard Deviations for Behavior assessment System Scores by Group and Time (Pre-Intervention versus Eight Weeks Post)

Behavior assessment System	Group	Pretest		Eight week post	
		M	*SD*	*M*	*SD*
Externalized	Usual care	50.30	8.63	48.30	12.07
	Intervention	47.91	21.39	55.00	15.08
	Total	49.05	16.24	51.81	13.82
Internalized	Usual care	48.30	12.07	48.00	11.47
	Intervention	55.00	15.08	47.91	24.56
	Total	51.81	13.82	47.95	19.00
Behavioral	Usual care	48.00	11.47	45.10	9.85
	Intervention	47.91	24.56	54.64	19.36
	Total	47.95	19.00	50.10	15.96
Adaptive	Usual care	45.10	9.85	55.30	12.69
	Intervention	54.64	19.36	53.00	24.36
	Total	50.10	15.96	54.10	19.25

One Week Posttest versus Eight Week Posttest. In order to assess if there were statistically significant differences between behavior assessment system scores (externalizing, internalizing, behavioral, and adaptive) by group (usual care versus intervention) and by time (one week post versus eight week post), a one-between, one-within multivariate analysis of variance (MANOVA) was conducted. In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test for equality of variance was not significant for any score, verifying the assumption of equality of variance. Normality was

assessed with eight Kolmogorov Smirnov tests, which were all not significant, verifying the assumption of normality.

The main effect of time was not significant, F (4, 17) = 1.00, p = .437, indicating simultaneous differences did not exist on behavior assessment system scores by time. The main effect of group was not significant, F (4, 17) = 2.52, p = .080, indicating that simultaneous differences did not exist behavior assessment system scores by group. The effect of the interaction was not significant, F (4, 17) = 1.06, p = .405, indicating that simultaneous differences did not occur from the interaction of time and group. The individual ANOVAs are presented in Table 32. The means and standard deviations for state and trait anxiety inventory scores by group and time are presented in Table 33.

Table 32

Individual ANOVAs on Behavior assessment System Scores by Group and Time (One Week Post versus Eight Weeks Post)

Source	Measure	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Between-Subjects								
Group	Externalized	1	168.09	168.09	0.57	.460	0.03	0.11
	Internalized	1	1331.00	1331.00	2.99	.099	0.13	0.38
	Behavioral	1	152.82	152.82	0.28	.604	0.01	0.08
	Adaptive	1	882.02	882.02	4.71	.042	0.19	0.54
Error	Externalized	20	5934.64	296.73				
	Internalized	20	8890.73	444.54				
	Behavioral	20	11018.36	550.92				
	Adaptive	20	3743.46	187.17				
Within-Subjects								
Time	Externalized	1	1.46	1.46	0.08	.779	0.00	0.06
	Internalized	1	76.46	76.46	0.72	.407	0.04	0.13
	Behavioral	1	56.82	56.82	0.77	.390	0.04	0.13
	Adaptive	1	14.21	14.21	2.49	.130	0.11	0.32
Time*Group	Externalized	1	40.09	40.09	2.22	.151	0.10	0.30
	Internalized	1	124.46	124.46	1.17	.293	0.06	0.18
	Behavioral	1	29.46	29.46	0.40	.534	0.02	0.09
	Adaptive	1	5.11	5.11	0.90	.355	0.04	0.15
Error	Externalized	20	360.46	18.02				
	Internalized	20	2131.09	106.56				
	Behavioral	20	1468.73	73.44				

Table 32 cont.

	Adaptive	20	114.18	5.71				

Table 33

Means and Standard Deviations for Behavior assessment System Scores by Group and Time (One Week Post versus Eight Weeks Post)

Behavior assessment System	Group	One week post		Eight weeks post	
		M	*SD*	*M*	*SD*
Externalized	Usual care	51.45	12.56	49.18	11.82
	Intervention	53.45	10.23	55.00	15.08
	Total	52.45	11.22	52.09	13.55
Internalized	Usual care	49.18	11.82	46.27	10.20
	Intervention	55.00	15.08	53.91	16.73
	Total	52.09	13.55	50.09	14.07
Behavioral	Usual care	46.27	10.20	40.27	18.54
	Intervention	53.91	16.73	54.64	19.36
	Total	50.09	14.07	47.45	19.90
Adaptive	Usual care	40.27	18.54	52.82	14.66
	Intervention	54.64	19.36	58.18	15.44
	Total	47.45	19.90	55.50	14.95

Research Question 2

Research question 2 (parts a, b, and c) examined the attrition rate by investigating which variables were predictors of one-week or eight-week program completion. The predictor variables included the demographics and mother and father anxiety (state and trait) and

depression scores. The outcome variables were completion of program at one week (wave two) or eight weeks (wave three), coded as 0 = no and 1 = yes. Demographics were coded as follows: parent's gender, female = 0, male = 1; parent's age, older than 30 = 0, 30 and younger = 1; child's age, 4 years and older = 0, 3 years and younger = 1; race, not white = 0, white = 1; marital status, not married = 0, married = 1; parent's education, no degree = 0, Bachelor's or higher = 1; parent's income, less than $75, 000 = 0, $75,000 and up = 1. Anxiety and depression scores were interval variables.

Research Question 2a. Which of the demographic variables, if any, predict one-week or eight-week program completion?

The results of the binary logistic regression with demographics predicting wave two completion were significant, χ^2 (7) = 15.20, p = .034, indicating that the demographics as a group contributed to the prediction of the completion of the wave two. However, further examination of the beta coefficients showed that none of the demographic variables predicted completion independently. Results of the binary logistic regression with demographics predicting wave two completion are presented in Table 34.

Table 34

Binary Logistic Regression with Demographics Predicting Wave two Completion

Predictor	*B*	*SE*	*p*	exp(B)
Parent's Gender	1.45	1.00	.147	4.24
Parent's Age	0.02	0.95	.985	1.02
Child's Age	-0.23	0.89	.798	0.80
Race	-22.07	17593.76	.999	0.00
Marital Status	20.45	17593.76	.999	7.58E+08
Education	-0.33	0.97	.735	0.72
Income	-1.06	1.11	.339	0.35

The results of the binary logistic regression with demographics predicting wave three completion were not significant, χ^2 (7) = 5.64, p = .582, indicating that the demographics did not predict the completion of wave three. Results of the binary logistic regression with demographics predicting wave three completion are presented in Table 35.

Table 35

Binary Logistic Regression with Demographics Predicting Wave three Completion

Predictor	*B*	*SE*	*p*	exp(B)
Parent's Gender	0.68	0.89	.442	1.98
Parent's Age	0.17	0.76	.823	1.19
Child's Age	0.39	0.73	.591	1.48
Race	0.61	1.43	.669	1.84
Marital Status	-1.48	1.29	.249	0.23
Education	0.27	0.88	.759	1.31
Income	-0.63	0.99	.522	0.53

Research Question 2b. Do mothers' anxiety and depression scores predict one-week or eight-week program completion?

The results of the binary logistic regression with mother's anxiety (state and trait) and depression scores predicting wave two completion was not significant, χ^2 (3) = 1.52, p = .677, indicating that, for mothers, anxiety and depression scores did not predict wave two completion. Results of the binary logistic regression with mothers' anxiety and depression scores predicting wave two completion are presented in Table 36.

Table 36

Binary Logistic Regression with Mothers' Anxiety and Depression scores Predicting Wave two Completion

Predictor	*B*	*SE*	*p*	exp(B)
State Anxiety	0.00	0.05	.936	1.00
Trait Anxiety	-0.07	0.07	.311	0.93
BDI	0.07	0.07	.376	1.07

The results of the binary logistic regression with mother's anxiety (state and trait) and depression scores predicting wave three completion was not significant, χ^2 (3) = 0.46, p = .929, indicating that the mother's anxiety (state and trait) and depression scores did not predict wave three completion. Results of the binary logistic regression with mother's anxiety (state and trait) and depression scores predicting wave three completion are presented in Table 37.

Table 37

Binary Logistic Regression with Mothers' Anxiety and Beck Depression Scores Predicting Wave three Completion

Predictor	*B*	*SE*	*p*	exp(B)
State Anxiety	0.00	0.05	.989	1.00
Trait Anxiety	0.04	0.06	.555	1.04
BDI	-0.03	0.07	.613	0.97

Research Question 2c. Do fathers' anxiety and depression scores anxiety and depression scores predict one-week or eight-week program completion?

The results of the binary logistic regression with fathers' anxiety (state and trait) and depression scores predicting wave two completion was not significant, χ^2 (3) = 3.98, p = .264, indicating that fathers' anxiety and depression scores did not predict the completion of wave two. Results of the binary logistic regression with fathers' anxiety and depression scores predicting wave two completion are presented in Table 38.

Table 38

Binary Logistic Regression with Fathers' Anxiety and Beck Depression Scores Predicting Wave two Completion

Predictor	*B*	*SE*	*p*	exp(B)
State Anxiety	0.09	0.09	.315	1.09
Trait Anxiety	-0.16	0.13	.203	0.85
BDI	0.25	0.18	.153	1.29

The results of the binary logistic regression with fathers' anxiety (state and trait) and depression scores predicting wave three completion was not significant, χ^2 (3) = 3.98, p = .264, indicating that fathers' anxiety and depression scores did not predict completion of wave three. Results of the binary logistic regression with d fathers' anxiety and depression scores predicting wave three completion are presented in Table 39.

Table 39

Binary Logistic Regression with Fathers' Anxiety and Beck Depression Scores Predicting Wave three Completion

Predictor	*B*	*SE*	*p*	exp(B)
State Anxiety	0.00	0.05	.989	1.00
Trait Anxiety	0.04	0.06	.555	1.04
BDI	-0.03	0.07	.613	0.97

Research Question 3. At pretest, is there a statistically significant difference in children's behavior problems (externalizing, internalizing, behavioral, and adaptive) by parent (mother versus father)?

In preliminary analysis, the assumptions of equality of variance and normality were assessed. The Levene's test for equality of variance was not significant for any score, verifying the assumption of equality of variance. Normality was assessed with eight Kolmogorov Smirnov tests, which were all not significant, verifying the assumption of normality.

The results for the MANOVA were not significant, F (4, 39) = 1.35, p = .268, indicating that simultaneous differences do not exist on behavior assessment system scores by parent gender. Individual ANOVAs are presented in Table 40. Means and standard deviations for behavior assessment system scores by parent gender are presented in Table 41.

Table 40

ANOVAs on Behavior Assessment System Scores by Parent Gender

Source	Measure	*df*	*SS*	*MS*	*F*	*p*	Partial η^2	Power
Parent gender	Externalizing	1	140.21	140.21	0.72	.402	0.02	0.13
	Internalizing	1	2.29	2.29	0.01	.931	0.00	0.05
	Behavioral	1	574.58	574.58	1.53	.223	0.04	0.23
	Adaptive	1	120.07	120.07	0.45	.506	0.01	0.10
Error	Externalizing	42	8216.43	195.63				
	Internalizing	42	12603.44	300.08				
	Behavioral	42	15754.97	375.12				
	Adaptive	42	111220.57	267.16				

Table 41

Means and Standard Deviations for Behavior Assessment System Scores by Parent Gender

Behavior assessment System	Gender	*M*	*SD*
Externalized	Female	50.31	15.05
	Male	45.89	8.01
	Total	49.41	13.94
Internalized	Female	48.34	18.93
	Male	47.78	7.24
	Total	48.23	17.12
Behavioral	Female	51.51	19.08
	Male	42.56	20.57
	Total	49.68	19.49
Adaptive	Female	38.57	15.48
	Male	42.67	19.60
	Total	39.41	16.24

Research Question 4. At pretest, do mothers' scores on the anxiety and depression scales predict children's behavior problems (externalizing, internalizing, behavioral, and adaptive)?

The first regression examined the impact of mothers' anxiety (state and trait) and depression scores on externalizing problems. In preliminary analysis, the assumptions of regression were assessed. The assumption of multicollinearity, normality, and homoscedasticity were met. The results of the multiple regression for externalizing behavior assessment system scores were not significant, F (3, 32) = 0.74, p = .536, indicating that the independent variables

did not predict externalizing problems. Results of the multiple regression are presented in Table 42.

Table 42

Multiple Regression with Mothers' Anxiety Scores (State and Trait) Predicting Externalizing Behavior Assessment System Scores

Variable	*B*	*SE B*	β	*t*	*p*
State Anxiety	-0.41	0.34	-0.30	-1.19	.242
Trait Anxiety	0.25	0.44	0.16	0.56	.583
BDI	0.41	0.49	0.22	0.85	.403

Note. $R^2 = .07$

The second regression examined the impact of mothers' anxiety (state and trait) and depression scores on internalizing problems. In preliminary analysis, the assumptions of regression were assessed. The assumption of multicollinearity, normality, and homoscedasticity were met. The results of the multiple regression for internalizing behavior assessment system scores were not significant, F (3, 31) = 0.84, p = .481, indicating that mothers' anxiety (state and trait) and depression scores did not predict internalizing problems. Results of the multiple regression are presented in Table 43.

Table 43

Multiple Regression with Mothers' Anxiety Scores (State and Trait) Predicting Internalizing Behavior Assessment System Scores

Variable	*B*	*SE B*	β	*t*	*p*
State Anxiety	-0.36	0.45	-0.21	-0.80	.429
Trait Anxiety	0.00	0.57	0.00	0.00	.997
BDI	0.83	0.62	0.35	1.34	.191

Note. $R^2 = .08$

The third regression examined the impact of mothers' anxiety (state and trait) and depression scores on behavioral scores. In preliminary analysis the assumptions of regression were assessed. The assumption of multicollinearity, normality, and homoscedasticity were met. The results of the multiple regression for behavioral scores for mothers were not significant, $F(3, 32) = 0.86$, $p = .472$, indicating that mothers' anxiety (state and trait) and depression scores did not predict behavioral scores. Results of the multiple regression are presented in Table 44.

Table 44

Multiple Regression with Mothers' Anxiety Scores (State and Trait) Predicting Behavioral Behavior Assessment System Scores

Variable	*B*	*SE B*	β	*t*	*p*
State Anxiety	-0.57	0.44	-0.33	-1.32	.198
Trait Anxiety	0.04	0.56	0.02	0.06	.950
BDI	0.72	0.62	0.30	1.17	.252

Note. $R^2 = .08$

The last regression examined the impact of mothers' anxiety (state and trait) and depression scores on adaptive behavior. In preliminary analysis, the assumptions of regression were assessed. The assumption of multicollinearity, normality, and homoscedasticity were met. The results of the multiple regression for adaptive behavior assessment system scores for mothers were not significant, F (3, 32) = 1.13, p = .351, indicating that mothers' anxiety (state and trait) and depression scores did not predict adaptive behavior assessment system scores. Results of the multiple regression are presented in Table 45.

Table 45

Multiple Regression with Anxiety Scores (State and Trait) Predicting Adaptive Behavior Assessment System Scores for Mothers

Variable	*B*	*SE B*	β	*t*	*p*
State Anxiety	-0.20	0.35	-0.14	-0.56	.582
Trait Anxiety	-0.54	0.45	-0.34	-1.19	.243
BDI	0.49	0.50	0.26	0.99	.329

Note. R^2 = .10

Research Question 5. At pretest, do father's scores on the anxiety and depression scales predict children's behavior problems (externalizing, internalizing, behavioral, and adaptive)?

The first regression examined the impact of fathers' anxiety (state and trait) and depression scores on externalizing problems. In preliminary analysis, the assumptions of regression were assessed. The assumption of multicollinearity, normality, and homoscedasticity were met. The results of the multiple regression for externalizing problems were not significant, F (3, 5) = 0.29, p = .832, indicating that fathers' anxiety (state and trait) and depression scores

did not predict externalizing behavior assessment system scores. Results of the multiple regression are presented in Table 46.

Table 46

Multiple Regression with Fathers' Anxiety Scores (State and Trait) Predicting Externalizing Behavior Assessment System Scores

Variable	*B*	*SE B*	β	*t*	*p*
State Anxiety	-0.22	0.25	-0.37	-0.86	.431
Trait Anxiety	-0.01	0.37	-0.02	-0.03	.974
BDI	0.19	0.53	0.20	0.35	.742

Note. $R^2 = .15$

The second regression examined the impact of fathers' anxiety (state and trait) and depression scores on internalizing problems. In preliminary analysis, the assumptions of regression were assessed. The assumption of multicollinearity, normality, and homoscedasticity were met. The results of the multiple regression for internalizing problems were not significant, $F(3, 5) = 3.91$, $p = .088$, indicating that fathers' anxiety (state and trait) and depression scores did not predict internalizing behavior assessment system scores. Results of the multiple regression are presented in Table 47.

Table 47

Multiple Regression with Fathers' Anxiety Scores (State and Trait Predicting Internalizing Behavior Assessment System Scores

Variable	*B*	*SE B*	β	*t*	*p*
State Anxiety	0.06	0.14	0.11	0.44	.677
Trait Anxiety	0.57	0.20	1.03	2.92	.033
BDI	-0.34	0.29	-0.41	-1.19	.287

Note. $R^2 = .70$

The third regression examined the impact of fathers' anxiety (state and trait) and depression scores on behavioral scores. In preliminary analysis the assumptions of regression were assessed. The assumption of multicollinearity, normality, and homoscedasticity were met. The results of the multiple regression for behavioral behavior assessment system scores for fathers were not significant, $F(3, 5) = 0.26$, $p = .852$, indicating that fathers' anxiety (state and trait) and depression scores did not predict behavioral behavior assessment system scores. Results of the multiple regression are presented in Table 48.

Table 48

Multiple Regression with Fathers' Anxiety Scores (State and Trait Predicting Behavioral Behavior Assessment System Scores

Variable	*B*	*SE B*	β	*t*	*p*
State Anxiety	0.51	0.65	0.34	0.77	.474
Trait Anxiety	0.07	0.95	0.04	0.07	.947
BDI	0.10	1.38	0.04	0.08	.943

Note. $R^2 = .37$

The last regression examined the impact of fathers' anxiety (state and trait) and depression scores on adaptive behavior. In preliminary analysis, the assumptions of regression were assessed. The assumption of multicollinearity, normality, and homoscedasticity were met. The results of the multiple regression for adaptive behavior assessment system scores were not significant, F (3, 5) = 1.62, p = .297, indicating that fathers' anxiety (state and trait) and depression scores did not predict adaptive behavior. Results of the multiple regression are presented in Table 49.

Table 49

Multiple Regression with Fathers' Anxiety Scores (State and Trait) Predicting Adaptive Behavior Assessment System Scores

Variable	*B*	*SE B*	β	*t*	*p*
State Anxiety	1.00	0.48	0.70	2.09	.091
Trait Anxiety	-0.36	0.69	-0.24	-0.52	.624
BDI	0.59	1.01	0.26	0.58	.585

Note. R^2 = .70

CHAPTER VI

Discussion

The COPE intervention has been successful when used with mothers and fathers of healthy children who were admitted to an intensive care setting to manage acute episodic medical or surgical issues. This study was designed to test the efficacy of the COPE intervention with parents of children with neurological conditions. There are a limited number of intervention studies that have addressed coping-related issues experienced by families of chronically ill children. To advance the science of pediatric nursing, nurses need knowledge and sound evidence to guide care implementation that best helps these families manage the complicated day-to-day experiences of caring for a chronically ill child.

This chapter will examine the study findings and address the limitations of the current study as well as discuss meaning of the findings, and implications for future theory, research, and practice.

Review of Study Findings

The specific aim of this study was to test the efficacy of the COPE intervention with parents of children with neurological conditions who are transitioning to home after hospitalization for diagnosis and/or treatment of their condition.

Discussion of Research Questions

Research Question 1a. Is there a statistically significant difference in parental belief in parenting skills between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

As reported in Chapter 5, the analysis of variance (ANOVA) revealed that the main effects of time (p = .094), group (p = .669), and interaction (p = .077) on parent confidence were not significant for pre-test versus one week post intervention, pre-test versus eight weeks post intervention, or one week versus eight weeks post intervention. Although there was no statistical significance, there was an overall trend toward significance among participants in the Intervention Group. When comparing parental belief scores from one week to eight weeks after transition to home, mean scores for parental belief in the Intervention Group increased from 71.82 to a score of 79.09 and decreased in the Usual Care Group from 78.64 to 69.64. These findings support the idea that the COPE intervention did have an impact on parent's confidence as scores on the Parental Beliefs Scale increased for parents in the Intervention Group only.

The goal of the COPE intervention was to increase parent confidence in their parenting skills by providing education designed to teach parents how to help their child cope with hospitalization. Children with neurological conditions experience frequent hospitalizations during which they undergo many medical procedures. Parents are often unsure how to help their child during these events and thus lose confidence in their parenting skills. As a result, the parent and child may both view the procedure as a stressful event. According to self-regulation theory, if the parent interprets the event as stressful, they will have a negative reaction to it. The COPE intervention provides the parent with information on what to expect from their child during a medical procedure and teaches them specific strategies to help make the experience more positive and less traumatic. This is important for parents of children with neurological conditions as they will continue to experience repeated hospitalizations over the course of their illness. Relying on self-regulation theory, the COPE intervention allows parents to adapt their parenting skills be learning coping strategies that they can use during similar episodes in the

future. Unfortunately, the education provided did not significantly increase the belief parents had in their ability to manage their child's responses to the management of their condition.

The COPE intervention may not be successful with parents of children with neurological conditions because parent confidence is dependent on a variety of factors and education alone is often not enough to significantly impact their parenting role (McNelis, Buelow, Myers, & Johnson, 2007; Rodenburg et al., 2007). The COPE intervention was initially successful with parents of healthy children who were hospitalized for acute illness events (Melnyk et al., 1997). For these parents the COPE intervention may have been successful because their priority was to facilitate coping for their child during the acute hospitalization. For parents of children with neurological conditions, they are going to leave the hospital with a child who will continue to have ongoing medical complications and their priorities may be quite different. Parents of children with neurological conditions are faced with many challenges on a daily basis and the information provided in the COPE intervention applies to general hospital information and does not address many of the needs of this vulnerable population. In addition to education regarding medical procedures, they also have physical, financial, and psychological needs that are not addressed as part of the COPE intervention (McNelis et al., 2007; Buelow et al., 2006). It is important to identify what parents prioritize as their education and/or supportive needs when caring for a child with a chronic condition as the information provided in the COPE intervention was not enough.

According to self-regulation theory, parents assess a situation by comparing the outcome to standards they themselves have set. These standards are based on what is important to the parent (Nerenz & Leventhal, 1983). These standards may be different for parents of chronically ill children and therefore not addressed by the information provided by the COPE intervention.

The COPE intervention lacks a mechanism for providing support and access to additional resources that may have been an important factor why parents in this study continued to have difficulty maintaining belief in their parenting role and may have impeded them from obtaining greater benefit from this study. Confidence is increased when you view yourself as successful based on your standards of what defines a positive outcome. Parents of children with neurological conditions may believe success is adequate seizure management or maintaining safety for their child. They may not consider facilitating coping as a priority for a successful outcome. This may be why confidence was not increased in all participants.

It is important to note that parents in both the Intervention Group and the Usual Care Group had moderate scores (M = 73.95) on the Parental Beliefs Scale at pretest indicating that overall, participants had moderate levels of confidence on how to parent their children during medical procedures. This scale was designed to measure parental beliefs about their role during the child's hospitalization with higher total scores indicating more parental belief in caregiving skills (Melnyk et al., 2007; 2004). In the current study, parent scores on the Parental Beliefs Scale did not significantly change over time (p = .549). This finding is consistent with findings in the literature that parents of chronically ill children often struggle with how to continue their normal parenting role (Rodenburg et al., 2011; Mu & Chang, 2010).

Parents of chronically ill children have a tendency to become overprotective and the COPE intervention asks parents to talk with their child about their experiences surrounding the hospitalization and medical procedures (Melnyk, 1997). This may have been uncomfortable for parents who have a tendency to protect their child from any additional harm or emotional upset. Parents did express that they did not think the information presented in the COPE intervention was appropriate for their child as they did not feel that their child was experiencing any stress

related to their condition or the hospitalization. Parents may believe that based on the developmental level or age of their child, the child does not have the ability to be affected by the stressful hospital experience. Children may have been exhibiting concerning behaviors that the parents either did not witness or did not appreciate as being a reaction to stress. The specific reasons behind these concerns were not addressed as part of the current study, but do warrant further investigation.

The COPE intervention does provide general information about child reactions to hospital associated stress, but parents need to have a good understanding of this concept and feel it is something important that needs to be addressed for the well-being of their child. Parents are unlikely to participate and find the COPE intervention helpful if they do not first acknowledge that the information presented is something that could benefit their family.

It is possible that both children with chronic conditions and their parents are used to being in the hospital and may even feel more comfortable in the hospital where healthcare providers are present and therefore, may not be able to appreciate the stress associated with the hospital experience. According to self-regulation theory, parents learn coping strategies from past experiences (Nerenz & Leventhal, 1983). The majorities of families in this study have experienced prior hospitalizations and may have already had the opportunity to develop positive coping strategies to be able to manage the stress associated with the hospitalization.

Research Question 1b. Is there a statistically significant difference in parent depression between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

As reported in Chapter 5, the ANOVA revealed that the main effects of time (p = .077) and group (p = .615) on parent depressive symptoms were not significant for pre-test versus one week post intervention, pre-test versus eight weeks post intervention, or one week versus eight weeks post intervention. These findings support that participating in the COPE intervention did not significantly decrease the report of depressive symptoms in parents.

Participants in both the Intervention Group and the Usual Care Group reported a range of depressive symptoms that were classified as mild to moderate, and in one case severe. Although the COPE intervention did not influence the degree of depressive symptoms reported by parents, it is important to note that many parents experienced some degree of depressive symptoms as noted by the scores on the BDI-II. Mean scores on the BDI-II ranged from 5.29 to 11.29 over the course of the study. A score between the ranges of zero to nine indicates minimal depression, but a score between the range of 10 and 18 indicates mild depression (Beck et al., 1996). These findings are consistent with studies in the literature that demonstrate that parents of children with neurological conditions often experience feelings of sadness or depression (Ferro et al., 2011; Mu, 2005; Tzoufi et al., 2005; Ferrari, 1989; Rutter et al., 1970).

According to self-regulation theory, parents need to appraise a situation to determine if their goals are being met; if not, they need to change their behavior in order to achieve the desired outcome (Nerenz & Leventhal, 1983). Parents who are experiencing depression may be unable to adequately interpret the situation and this may ultimately affect their response. The education provided by the COPE intervention was designed to indirectly decrease depression by increasing parent knowledge and positive coping strategies. However, before an educational intervention can be successful, parents need to successfully manage feelings of depression in order to be able to effectively interpret the situation. In the COPE intervention, direct causes of

depression are not explored and counseling is not routinely provided unless deemed necessary. The findings from this study do support the fact that parents of children with neurological conditions experience a variety of depressive symptoms that the COPE intervention was not designed to address.

Based on previous studies utilizing the COPE intervention, it would have been plausible to anticipate that the intervention would also have been effective in moderating depressive symptoms in the current study as well. Uncertainty and decreased belief in parenting ability may contribute to depression in parents of children with neurological conditions (Mu, 2005; Mu et al., 2005). Since the information in the COPE intervention is intended to address uncertainty and parenting ability, one could therefore assume depressive symptoms would decrease for parents in the Intervention Group. However, this was not the case in the current study. It is possible that factors contributing to depression among this group of parents were multifactorial and not fully addressed by the COPE intervention as the COPE intervention was not originally designed for parents of chronically ill children and it does not offer a full range of supportive resources to these parents.

The ANOVA did reveal that the interaction between time and group on parent depressive symptoms was significant ($p = .009$). Mean scores for parent depressive symptoms among the Usual Care Group were higher pre-intervention ($M = 11.29$) when compared to the scores one week after the intervention ($M = 5.29$). These findings suggest that for parents in the Usual Care Group, depressive symptoms were more common during the time of acute hospitalization. Ninety-one percent of children in the Usual Care Group had a diagnosis of seizures, compared to 59% in the Intervention Group. Children with epilepsy are often admitted to the hospital for seizure exacerbations. In this study, children with a diagnosis of seizures were having frequent

seizures during their hospitalization. Seizures are a physical neurological symptom that may produce worry and fear in parents and have a larger impact on rates of depression when compared to children with other diagnoses (Tzoufi, et al., 2005). It may have been that for parents in the Usual Care Group, depressive symptoms were highest during the hospitalization because they were witnessing their child have frequent seizures and therefore, their rates of depressive symptoms decreased without any intervention because their child's seizures were better controlled after hospital discharge. Correlates of parent depression would require further investigation in future studies as a causal effect cannot be assumed.

Research Question 1c. Is there a statistically significant difference in parental anxiety between each of the three time periods (pre-intervention versus one week post, pre-intervention versus eight weeks post, one week post versus eight weeks post) by group (usual care versus intervention)?

As reported in Chapter 5, the multiple analysis of variance (MANOVA) revealed that the main effect of time was significant for differences in state anxiety for both the Usual Care Group and the Intervention Group ($p = .005$). This finding indicates that mean scores of state anxiety for both groups combined was more pronounced at pre-intervention ($M = 42.32$) versus one week posttest ($M = 36.91$) and pre-intervention ($M = 42.32$) versus eight week posttest ($M = 34.50$). These findings support that parental anxiety in both the Intervention and Usual Care Groups was highest during the time of hospitalization.

These findings were not unexpected as the literature supports that the time of diagnosis and hospitalization is the time of greatest stress for parents (Aytch et al., 2001; Oostrom et al., 2001). Parenting a child acutely hospitalized with a neurological diagnosis produces anxiety related to management of the child's condition. This anxiety is often attributable to the

uncertainty of a child's prognosis when they are admitted to the hospital to manage neurological symptoms (Lv et al., 2009). Self-regulation dictates that a persons' response to a situation is determined by their interpretation of the event (Nerenz & Leventhal, 1983). When a child is admitted to the hospital with an uncertain prognosis, parents become anxious because they do not know what to expect and this negatively affects their ability to formulate a strategy for how to best deal with their current situation. Parental anxiety may decrease over time as the child responds to treatment and improves clinically resulting in less uncertainty, resulting in parents at becoming more comfortable in the caregiving role. Over time parents gain more experience and have the opportunity to apply the theory of self-regulation by learning to continually appraise their situation and reevaluate coping strategies allowing them to develop more positive strategies based on their positive or negative experiences (Nerenz & Leventhal, 1983).

The differences in trait anxiety over time were not significant ($p = .465$). The MANOVA revealed the main effect of group and interaction on trait anxiety was not significant when comparing pre-intervention versus one-week posttest. The main effects of group and interaction on trait anxiety during this time period were also not significant ($p = .6$). This was expected as the parent's trait anxiety is a reflection of their tendencies to be anxious, as opposed to being influenced by their experiences at the time. The COPE intervention is not designed to directly address preexisting anxiety symptoms or tendencies towards anxiety.

The MANOVA also revealed the main effects of time, group, and interaction were not significant ($p = .418$) when comparing one week posttest versus eight week posttest. These findings support that neither state nor trait anxiety changed during the time period between one week and 8 weeks following the hospitalization. This may indicate that there is a tremendous

amount of stress during the acute hospitalization that subsides after the child recovers and is well enough to be discharged home.

These findings have important implications for designing and implementing future research studies with this population of vulnerable parents as most education is provided to parents during the hospitalization when their anxiety level is at its' highest. This can interfere with their ability to learn and retain important information. Intervention studies need to acknowledge this and tailor the delivery of information to ensure parents are able to understand the information and feel they have the ability and confidence to utilize their knowledge to care for their child.

Research Question 1d. Is there a statistically significant difference between behavior assessment system scores (externalizing, internalizing, behavioral, and adaptive) by group (usual care versus intervention) and by time (pre-intervention versus one week post)?

As reported in Chapter 5, the MANOVA revealed the main effect of time was not significant (p = .187), and the main effect of group was not significant (p = .431) when comparing pretest versus one week posttest indicating that simultaneous differences did not exist by time or group. However, the effect of the interaction was significant for internalized behavior assessment system score only (p = .037) as the Usual Care Group reported a significant decrease in internalizing behavior scores in their children over time. These findings are difficult to interpret without further investigation, but do support the idea that children in the Usual Care Group experienced higher levels of internalizing behaviors (i.e. – anxiety) during the hospitalization. These findings indicate that hospitalization is stressful for children and it is not clear from the findings why child internalizing behaviors in the Usual Care Group changed without any intervention. Further information is needed to determine why the change in

behaviors occurred in this group, but not in the Intervention Group. The Usual Care Group was comprised of a higher percentage of children with seizures (91.7%) as compared to the Intervention Group (59.1%). Seizures are a frightening experience, even when it is a chronic issue. The increased internalizing behaviors in the children in the Usual Care Group during the acute hospitalization may have been secondary to the seizure diagnosis as children with epilepsy are noted to have higher incidences of behavior problems (Rodenburg et al., 2011; Berg et al., 2005; Oostrom et al., 2001; Austin & Dunn, 2000). Children who are hospitalized experience stress that may manifest as internalizing behaviors and this may naturally improve once their seizure activity is controlled and they are discharged home and out of the stressful environment of the hospital.

The MANOVA revealed the main effect of time was not significant (p = .551), and the main effect of group was not significant (p = .329) when comparing pretest versus eight week posttest indicating that simultaneous differences did not exist by time or group. The effect of the interaction was also not significant (p = .058). The MANOVA also revealed that the main effects were not significant for time (p = .437), group (p = .080), or interaction (p = .405) when comparing one week posttest versus eight week posttest. Again, these findings are difficult to interpret without further investigation. The fact that internalizing behaviors did decrease in both groups at some time after the hospitalization does indicate that children do experience some level of stress during the hospitalization, which may manifest itself as certain internalizing behavior problems. The COPE intervention is useful in that it provides parents with information on how to recognize certain clinical manifestations of internalizing behaviors their child may be experiencing as a result of the hospitalization including, bedwetting, sleep disturbances, and thumb sucking (Melnyk, 1997). The ability to recognize symptoms or negative behaviors is

necessary for an intervention based on self-regulation theory to be successful. When parents are able to recognize certain behaviors as problematic, they can rely on past experiences to help them develop successful strategies for dealing with the behaviors the child is displaying (Nerenz & Leventhal, 1983). Parents need to be able to identify these behaviors as ways in which stress reactions manifest themselves in children. The decrease in internalizing behavior problems is difficult to interpret without further study.

Research Question 2a. Which of the demographic variables, if any, predict one-week or eight-week program completion?

As reported in Chapter 5, the binary logistic regression with demographics predicting wave two completion was significant as a group ($p = .034$), though not independently. This finding supports the notion that although demographic variables had some effect on predicting which participants would complete the second phase of the study, it was not possible to determine which specific variables were responsible. It may be a combination of factors that influences a participants' decision or ability to complete phases of a research study. The binary logistic regression was not significant ($p = .582$) for predicting completion of wave three of the COPE intervention.

Research Question 2b. Do mothers' anxiety and depression scores predict one-week or eight-week program completion?

As reported in Chapter 5, the binary logistic regression was not significant ($p = .677$) indicating that mothers' anxiety and depression scores did not predict the completion of either wave two or three of the COPE intervention.

It may be expected that mothers with psychological stressors may be less able or willing to continue with the requirements of the COPE intervention. However, in this study, that was

not the case. There was only one participant in this study who was identified as having significant depressive symptoms. The small sample is a limitation and the noted incidence of both anxiety and depressive symptoms among this study population may not be representative of mothers of chronically ill children as a group. Mothers of chronically ill children have been noted to have an increased incidence of anxiety and depression (Tzoufi, et al., 2005). The ability to predict study completion may be influenced by these factors, but a larger sample would be needed to determine if a significant relationship exists.

Research Question 2c. Do fathers' anxiety and depression scores anxiety and depression scores predict one-week or eight-week program completion?

As reported in Chapter 5, the binary logistic regression was not significant ($p = .264$) indicating that fathers' anxiety and depression scores did not predict the completion of either wave two or three of the COPE Intervention. These findings suggest that the psychological state of the father did not influence their decision or ability to continue participation in the COPE Intervention.

These findings are limited by the small number of fathers included in the current study. None of the fathers in this study were identified as having significant anxiety or depressive symptoms. The decision to participate in pediatric research studies may be influenced by the psychological state of the father, but this needs to be investigated in future studies.

Research Question 3. At pretest, is there a statistically significant difference in children's behavior problems (externalizing, internalizing, behavioral, and adaptive) by parent (mother versus father)?

As reported in Chapter 5, the MANOVA revealed no significant difference ($p = .268$) between behavior assessment system scores across parent (mother-father) dyads. These findings

suggest that there was no difference between mothers' and fathers' assessment of their child's behavioral issues. Mothers and fathers equally recognized behavioral problems in their children and reported these on the BASC-2.

Medical care of the child with a neurological condition centers around diagnosis and treatment of epileptic seizures and other physical symptomatology. It does not often include the management of behaviors that occur as a result of the primary condition. The fact that both parents equally recognized these problems highlights the significance of this issue and that both clinical practice and future research studies should be designed to identify and manage behavior problems among children with epilepsy.

Research Question 4. At pretest, do mothers' scores on the anxiety and depression scales predict children's behavior problems (externalizing, internalizing, behavioral, and adaptive)?

As reported in Chapter 5, multiple linear regression revealed mothers' pretest anxiety (state and trait) and depression scores did not predict her child's externalizing, internalizing, behavioral, or adaptive behavior assessment system scores ($p = .536$). These findings suggest that child behavioral symptoms were not influenced by their mothers' level of anxiety and/or depressive symptoms.

Evidence in the literature supports a causal relationship between mothers' anxiety and depression and behavior problems in their child with epilepsy (Wirrell et al., 2008; Rodenburg et al., 2006; Low & Stocker, 2005; Austin et al., 2004). Findings from the current study may have not been significant as a result of an inadequate sample size. However, there are many factors that contribute to behavior problems in children with neurological conditions and the psychological state of the child's mother may not alone be a significant predictor. Children with

neurological conditions have a higher incidence of behavior problems than children with other chronic conditions (Rodenburg et al., 2011; Berg et al., 2005). Although mothers' anxiety and depression may have an influence on behavior problems in the child, social support and the family environment also have a significant effect on child behavior (Thornton et al., 2008; Austin et al., 2004). The current study was limited by the fact that it did not examine other potential factors related to child behavior problems.

Research Question 5. At pretest, do father's scores on the anxiety and depression scales predict children's behavior problems (externalizing, internalizing, behavioral, and adaptive)?

As reported in Chapter 5, multiple linear regression revealed fathers' pretest anxiety (state and trait) and depression scores did not predict externalizing, internalizing, behavioral, or adaptive behavior assessment system scores. These findings suggest that child behavior problems were not influenced by the psychological state of their fathers. Evidence supports that parental anxiety and/or depression may affect the parent-child relationship, which can result in negative behaviors in the child (Low & Stocker, 2005). The majority of current literature focuses on the psychological states of mother, and therefore little is known about the fathers' responses in these situations. In this study, there was no correlation between paternal anxiety or depression and the ability to predict child behavior problems.

Unfortunately, these findings underscore a significant issue within current family research literature. Very few existing studies include fathers and when they do they tend to be case series only. It is common in today's society for fathers to have a very active caregiving role. Fathers have a tremendous influence over their child's coping and involving them may result in a significant positive improvement in the child's behavior. The limited sample in this study makes it difficult to draw conclusions, but it is an important first step. Future research

needs to focus more attention on the relationship between fathers and coping of the chronically ill child.

Limitations

This study was limited by sample size as a result of changes in the delivery of care provided on the inpatient neuroscience unit as previously described in Chapter 4. Based on a medium effect size, it is possible that statistical significance for many of the proposed research questions may have been reached if the original proposed sample size had been attained. The initial proposed study inclusion criteria included parents of children with epilepsy who were being admitted to the inpatient neuroscience unit for long-term EEG monitoring. Unfortunately, as families were screened, many potential participants were excluded based on the child's developmental disabilities. There are many children with epilepsy who do not have developmental disabilities and could participate in the requirements of the COPE intervention. However, children with severe or intractable epilepsy often have significant existing co-morbidities including language delays (Daniel et al., 2008; Aldeklamp & Arends, 2004; Bailet & Turk, 2000), which would preclude them from being able to participate in the COPE Intervention. The COPE intervention consists of interactive play between parent and child. To successfully participate in the program, the child needed to be developmentally able to express their thoughts and emotions; therefore, the COPE intervention would not be recommended for use with children with developmental delays.

An additional limitation related to sample size was the small number of fathers who enrolled in the study. Fathers were more likely to consent to participate in the study, but fathers were often not present at the child's bedside and were therefore difficult to recruit. The small sample size significantly limits any interpretation of study results from the paternal perspective.

Although participant recruitment did improve after modifying the inclusion criteria for the study, attrition continued to be a significant limiting factor. Participants were asked to complete three phases of the COPE intervention over a twelve week period. Although 46 participants enrolled, only 21 completed all three phases. This limited the ability to study the effect of the COPE Intervention over time. The reasons for this high attrition rate are speculative and warrant further investigation. Parents may have decided not to continue their participation in the COPE intervention because they found the information provided to be limited and not relevant to their family. They may have discontinued their participation because the COPE Intervention lacks the emotional and social support they needed to be able to help their child cope with the hospitalization. Previous studies utilizing the COPE intervention have had attrition rates ranging from 15% to 67% (Melnyk et al., 2006; Melnyk et al., 2004). In both of these studies further analyses were conducted to determine if reasons for the rate of attrition could be identified. Factors predictive of attrition were not identified in either case (Melnyk et al., 2006; Melnyk et al., 2004).

Parents expressed an interest in the study, but the demands of work-life balance may have prevented them from ongoing participation in the study. Ancillary comments from parents indicated that they felt the information provided as part of the COPE intervention was not applicable to their child. They did not understand or recognize the fact that even though their child may be acting normally, the hospitalization was stressful for their child. They did not attribute certain behavioral changes in their child, like acting out, to stress from being in the hospital. Young children express stress in different ways and parents may not be aware of this and often think their pre-school aged child may be too young to be affected by these experiences.

This lack of knowledge regarding the effects of hospitalization on young children may have influenced their decision to not complete the study.

The content and mode of delivery in the COPE intervention was a limitation of this study. The COPE intervention does not address many areas of concern for parents of children with chronic conditions. Although parents of children with neurological conditions do need information pertaining to helping their children cope with medical procedures, their need for information regarding the medical management of their child's condition may be the priority. Phase I of the COPE intervention was administered during the hospitalization, which is a time of great stress since the child is often experiencing seizure exacerbation. Phase II and III were administered at home. This was a limiting factor as a research team member was not present to answer questions and explain the information in more detail if needed.

Another limitation was the fact that the measurement instruments were provided to participants on paper only and needed to be mailed back to the investigator. This placed an additional burden on parents; they may have been more likely to complete online versions of the questionnaires (Hunter, 2012). Also, the materials were only available in English and non-English speaking families were excluded, which again limited the sample from which to recruit participants. The fact that medical data was not collected at the time parents were asked to complete the instruments is another limitation of the study. This study did not use an objective measure to assess child behavior problems, but rather relied upon self-report data. This method of data collection has its' own limitations as based on social desirability; thus, parents may have underreported child behavior problems. These findings have several important implications for future research.

Implications for Theory, Research, and Practice

Theory

Self-regulation theory can be instrumental for parents caring for acutely ill children. When a child is experiencing an acute hospitalization for a specific condition, there are certain expectations and experiences associated with the acute event that allow parents to anticipate their child's needs. Parents learn how to interpret certain symptoms and behaviors that their child might be exhibiting as a result of the hospitalization or medical procedure. When parents recognize these problems, then they can draw on past experiences to know how to respond in a nurturing and supportive way. However, this is not the same as caring for a child with a chronic condition. Self-regulation theory may not be appropriate for managing chronic situations in which circumstances constantly change and are unpredictable.

Parents of children with neurological conditions need to constantly change their actions and responses based on their child's condition. For example, when a child has epilepsy it is not uncommon for seizure types to change as the child ages. Seizures can also be difficult to control and constant medication changes and additional testing can become a way of life. In these situations, an intervention based solely on self-regulation theory may not be realistic. Self-regulation theory requires a parent to draw on past experiences. Children with chronic neurological conditions do not have a predictable disease course and may often be faced with new situations or symptoms. The COPE intervention may help these families manage coping in their child during predictable experiences, like blood draws or CAT scans, but may not be helpful in managing the unknown.

A nursing-based theory-driven educational intervention needs to be designed to help families adjust to living with a child who has a chronic condition with an uncertain future.

Parents can be taught to identify and interpret certain cues or symptoms exhibited by their child in response to stressful situations, like a hospitalization, similar to the information provided by the COPE intervention. However, parents of children with chronic conditions also will need additional information related to the medical management (i.e. – seizure first aid) of their child's condition. In addition to a behavioral intervention, these parents need to also learn to recognize, interpret, and manage physical symptoms.

Beyond providing education to families, future studies need to design interventions based on the individual needs of the participants involved. Self-regulation is based on how the individual interprets the situation compared to what their goals are (Nerenz & Leventhal, 1983). Parents need guidance in determining what their goals are for their child and family and what they would consider a positive outcome. Then the nurse can work toward helping them strategize to attain those goals. Providing standard education to all parents without first assessing their needs and pre-existing coping strategies will not yield successful results for all families.

Research

Conducting research with families of children with chronic conditions poses several challenges related to recruitment and retention including, small populations, and lack of time and research knowledge on the part of the parents. As previously discussed in Chapter 4, this study identified several potential barriers to both recruitment and retention among parents of children with neurological conditions. The experiences of the current study have several important implications for future research with families of children with chronic conditions. Parents of children with chronic conditions often have limited time, support, and resources. Therefore, although they may be interested in participating in research, they may not be able to do so.

Studies need to be designed with this in mind and give parents every possible opportunity to be successful in research participation.

These issues may be addressed in several ways. Parents need to see meaning in research and may be more likely to participate if they understand the potential benefit. While introducing a research study to potential participants, time should be dedicated to explaining the research process in general and how findings from research studies effect future advancements in delivery of care. Researchers should be careful to describe the ways in which study findings influence the decisions we make regarding patient care.

Beyond understanding the research process, studies need to be designed that are practical for families caring for children with neurological conditions. Research studies should be designed to occur during clinic visits or at times convenient for the family. Offering financial incentives to help deal with additional costs, etc. Providing the opportunity for electronic correspondence is another example, which may relieve some of the burden associated with research participation. This may include using electronic versions of the measurement instruments as well.

Practice

The findings from this study have several implications for clinical practice. Young children living with neurological diagnoses often experience stress related to the management of their condition, which usually manifests as behavioral changes. Parents should be educated to help their child cope with their experiences, which can improve coping and functioning for the entire family.

Unfortunately, the findings from this study indicate that providing education related to coping with hospital experiences does not significantly improve coping in parents of children

with severe neurological conditions likely due to the limitations discussed above. Teaching parents of children with chronic conditions how to recognize and respond to certain behavioral changes in their child may help to promote positive coping in their child. However, the COPE intervention does not include the additional information or strategies needed to care for a child with a chronic condition at home. The first priority of these parents is to keep their child safe. Therefore, the information provided in the COPE intervention may not be seen as a priority. Parents are more concerned about the medical management of their child and may not understand that the stress related to the experience can have such a profound effect on the child. Nurses are in a position to recognize the need for parents to appreciate issues outside of medical management and can provide this education to families during their hospital stay. Nurses can demonstrate these coping strategies during medical procedures and help parents learn techniques that they can also continue after they have been discharged to home. It is difficult to incorporate the needs of a child with a chronic condition into day-to-day activities and nurses can help provide these families with resources and support that can help facilitate the transition.

Future Research

The findings from this study lay the groundwork for future research involving parents of children with chronic conditions. Parents experience an increased level of anxiety during a child's hospitalization. However, this acute period is when they are provided with education on how to care for their child at home. Children with neurological conditions are unique in the sense that they often experience exacerbations of their condition, which results in repeat hospitalizations. This is challenging for parents who now also need to know how to help their young child cope with hospital stays and medical procedures. The family is burdened with the responsibility of minimizing behavioral regression while helping to promote the cognitive and

emotional development of their child during these acute events. Parents often are not even aware of the effects a hospitalization may have on a young child. Future research needs to focus on the effects of repeated hospitalizations and determine how parents can help prepare their child for these repeated experiences. Currently, there are no published intervention studies that successfully provide this information for parents of children with neurological conditions. This is a population that presents unique challenges and future research should focus on how to best meet the needs of these families.

The majority of research involving children with chronic conditions involves mothers only. Mothers are often considered the primary caretaker and are often the parents present at the child's bedside during the hospitalization. However, this scenario is evolving as fathers are becoming more involved in the care of their children. In this study, recruitment with fathers was limited, but future research should address ways to improve recruitment of fathers into these important studies. Many of these families were two income households where both parents worked outside of the home. In these families, fathers have a significant role in the coping of their child.

Summary

The aim of this study was to test the efficacy of the COPE intervention with parents of children with neurological conditions. Unfortunately, the majority of findings from the study were not significant most likely due to the limited sample size.

Findings from this study highlight several important factors when considering research with families of chronically ill children. Parents of children with neurological conditions face many challenges on a daily basis. In addition to everyday child rearing practices, they also have to manage often complicated medical conditions. How parents respond to their child's needs and

experiences may additionally help the child cope with the experience of living with a chronic condition. This, in turn, has implications for improving the functioning of the entire family. Intervention research needs to be developed to facilitate the transition of care from hospital to home.

Transitional care is a complicated process by which family members become caregivers of patients with complicated healthcare needs. The Transitional Care Model has been developed to assist in this transition for elderly patients with chronic healthcare needs (Naylor, 2012). This model has been successful in reducing healthcare costs, preventing hospital readmissions, improving patient satisfaction, and improving health outcomes (Naylor, 2012). Although this model is designed for transitioning the care of older adults home, similar principles apply to the pediatric population. The transition from hospital to home is complicated. The Transitional Care Model requires a multidisciplinary approach where caregivers also become part of the healthcare team (Naylor, 2012). This is crucial for parents of children with chronic conditions as they know the care and needs of their child better than the healthcare providers. It is important for parents to develop a trusting relationship with their child's healthcare providers to help them manage the child's condition safely at home. However, as this study has identified, there are many confounding variables among this vulnerable population that makes research in this area challenging. Parents of children with chronic conditions differ from caregivers of the elderly. Parents of children with chronic conditions deal with uncertainty and unpredictability that results in additional stress. Parents are also faced with fostering the development of their child and managing behaviors, which has a significant impact on the successful transition to home. The transition from hospital to home is crucial for families of children with chronic conditions and healthcare providers are integral to the success or failure of this endeavor.

Further research in this area is needed. Findings from this study indicate that parents are interested in helping their children, but often have difficulty finding the time to participate in research related activities. Intervention studies need to be designed with this in mind as the information discovered through future studies may be invaluable.

Finally, the results from this study are useful to nursing practice. Nurses who care for these families need to be able to recognize that these families require additional education and support beyond medical management of the child's condition. Nurses can support these families and help teach them strategies to facilitate coping in their child. More and more children are living with chronic neurological conditions and continued research is necessary to help to improve the quality of their lives.

REFERENCES

Aldenkamp, A.P., & Arends, J. (2004). Effects of epileptiform EEG discharges on cognitive function. Is the concept of "transient cognitive impairment" still valid? *Epilepsy & Behavior, 1*, S25-34.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: American Psychiatric Association.

American Psychological Association. (2013). Understanding Chronic Stress. American Psychological Association. Retrieved January 26, 2013, from http://www.apa.org/helpcenter/understanding-chronic-stress.aspx

Austin, J.K. (1988). Childhood epilepsy; child adaptation and family resources. *Journal of Child & Adolescent Psychiatric & Mental Health Nursing, 1*(1), 18-24. doi: 10.1111/j.1744-6171.1988.tb00222.x

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

Austin, J.K., Smith, M.S., Risinger, M.W., & McNelis, A.M. (1994). Childhood epilepsy and asthma: comparison of quality of life. *Epilepsia, 35*(3), 608-615. doi: 10.1111/j.1528-1157.1994.tb02481.x

Austin, J.K., & Dunn, D.W. (2000). Children with epilepsy: Quality of life and psychosocial needs. *Annual Review of Nursing Research, 18*, 26-47.

Austin, J.K., Harezlak, J., Dunn, D.W., Huster, G.A., Rose, D.F., & Ambrosius, W.T. (2001). Behavior problems in children before first recognized seizure. *Pediatrics, 107*(1), 115-122. doi: 10.1542/peds.107.1.115

Austin, J.K., McNelis, A.M., Shore, C.P., Dunn, D.W., & Musick, B. (2002). A feasibility study of a family seizure management program: "Be Seizure Smart." *Journal of Neuroscience Nursing, 34*(1), 30-37.

Austin, J.K., Dunn, D.W., Johnson, C.S., & Perkins, S.M. (2004). Behavioral issues involving children and adolescents with epilepsy and the impact of their families; recent research data. *Epilepsy & Behavior, 5*, S33-S41. doi: 10.1016/j.yebeh.2004.06.014

Aytch, L.S., Hammond, R., & White, C. (2001). Seizures in infants and young children: An exploratory study of family experiences and the needs for information and support. *Journal of Neuroscience Nursing, 33*(5), 278-290.

Baca, C.B., Vickrey, B.G., Caplan, R., Vassar, S.D., Berg, A.T. (2011). Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. *Pediatrics. 128*(6):e1532-43.

Bachanas, P.J., Kullgren, K.A., Schwartz, K.S., Lanier, B., McDaniel, J.S., Smith, J., & Nesheim, S. (2001). Predictors of psychological adjustment in school-age children infected with HIV. *Journal of Pediatric Psychology, 26*(6), 343-352.

Bailet, L., & Turk, W.L. (2000). The impact of childhood epilepsy on neurocognitive and behavioral performance. *Epilepsia, 41*, 426-431.

Baquet, C.R., Henderson, K., Commiskey, P., & Morrow, J.N. (2008). Clinical trials: the art of enrollment. *Seminars in Oncology Nursing, 24*(4), 262-269.

Bazil, C.W. (2004). Comprehensive care of the epilepsy patient – control, comorbidity, and cost. *Epilepsia, 45*, 3-12.

Beck, A. T., Steer, R. A., & Brown, G. K. (1996). *Manual for the Beck Depression*

Inventory. (2nd ed.). San Antonio: The Psychological Corporation.
Berg, A.T., Smith, S.N., Frobish, D., Levy, S.R., Testa, F.M., Beckerman, B., Shinnar, S. (2005). Special education needs of children with newly diagnosed epilepsy. *Developmental Medicine & Child Neurology, 47*, 749-753.
Bruzzese, J.M., Gallagher, R., McCann-Doyle, S., Reiss, P.T., Wjetunga, N.A. (2009). Effective methods to improve recruitment and retention in school-based substance use prevention studies. *Journal of School Health, 79*(9), 400-407.
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), 147-154.
Burke, S.O., Kauffmann, E., Costello, E.A., & Dillon, M.C. (1991). Hazardous secrets and reluctantly taking charge: parenting a child with repeated hospitalizations. *Image: Journal of Nursing Scholarship, 23*(1), 39-45.
Carlton-Ford, S., Miller, R., Nealeigh, N., & Sanchez, N. (1997). The effects of perceived stigma and psychological over-control on the behavioral problems of children with epilepsy. *Seizure, 6*(5), 389-391.
Carver, C.S. (1979). A cybernetic model of self-attention processes. *Journal of Personality and Social Psychology, 37*(8), 1251-1281.
Carver, C.S., & Scheier, M.F. (1982). Control theory: a useful conceptual framework for personality-social, clinical, and health psychology. *Psychological Bulletin, 92*(1), 111-135.
Chang, B.H., Hendricks, A.M., Slawsky, M.T. & Locastro, J.S. (2004). Patient recruitment to a randomized clinical trial of behavioral therapy for chronic heart failure. *BMC Medical Research Methodology*, 4-8.
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*, 246-252. doi: 10.1016/j.yebeh.2005.05.002
Chiou, H.H. & Hsieh, L.P. (2008). Comparative study of children's self-concepts and parenting stress between families of children with epilepsy and asthma. *Journal of Nursing Research, 16*(1), 65-74.
Clarke-Steffan, L. (1993). Waiting and not knowing: the diagnosis of cancer in a child. *Journal of Pediatric Oncology Nursing, 10*(4), 146-153.
Clements, D.B., Copeland, L.G., & Loftus, M. (1990). Critical times for families with chronically ill child. *Pediatric Nursing, 16*(2), 157-161.
Cobham, V.E., Dadds, M.R., & Spence, S.H. (1998). Role of parental anxiety in the treatment of childhood anxiety. *Journal of Consulting and Clinical Psychology, 66*, 893-905.
Cohen. H., & Martinson, I.M. (1988). Chronic uncertainty: Its effect on parental appraisal of a child's health. *Journal of Pediatric Nursing, 3*(2), 89-96.
Cohen, M.H. (1993). Diagnostic closure and the spread of uncertainty. *Issues in Comprehensive Pediatric Nursing, 16*(3), 135-146.
Cohen, M.H. (1995). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. *Qualitative Healthcare Research, 5*(1), 63-77.
Cotter, R.B., Burke, J.D., Stouthamer-Loeber, M. & Loeber, R. (2005). Contacting participants for follow-up: how much effort is required to retain participants in longitudinal studies?

Evaluation and Program Planning, 28, 15-21.
Cushner-Weinstein, S., Dassoulas, K., Salpekar, J.A., Henderson, S.E.,Pearl, P.L., Gaillard, W.D., and Weinstein, S.L. (2008). Parenting stress and childhood epilepsy: the impact of depression, learning, and seizure-related factors. *Epilepsy & Behavior, 13*, 109-114. doi: 10.1016/j.yebeh.2008.03.010
Daniel, R., Russell, P., & Thomas, S. (2008). Cognitive development and pediatric epilepsy surgery. *Journal of Pediatric Neurosciences, 3*, 30.
DiFazio, R. & Vessey, J. (2011). Nonmedical out-of-pocket expenses: a hidden cost of hospitalization. *Journal of Pediatric Nursing, 26*(11), 78-84.
Ely, B., Coleman, C. & Kotzer, A.M. (2007). Scientific inquiry. Recruitment and retention of children in longitudinal research. *Journal for Specialists in Pediatric Nursing, 12*(3), 199-202.
Epilepsy Foundation of America®. (2011, March 22). Epilepsy and Seizure Statistics. *Epilepsy Foundation®.* Retrieved March 22, 2011, from http://www.epilepsyfoundation.org/about/statistics.cfm
Ferrari, M. (1989). Epilepsy and its effects on the family. *Childhood Epilepsies: Neurological, Psychological, and Intervention Aspects, edited by BP Hermann and M. Seidenberg. New York: Wiley*, 159-72.
Ferro, M.A., Avison, W.R., Campbell, K., and Speechley, K.N. (2011). Prevalence of trajectories of depressive symptoms in mothers of children with newly diagnosed epilepsy. *Epilepsia, 52*(2), 326-336.
Fisher, R.S., van Emde Boas, W., 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.
Flanagan, R. (1995). A review of the behavior assessment system for children (BASC): Assessment consistent with the requirements of the individuals with disabilities education act (I DEA). *Journal of School Psychology, 33*(2), 177-186.
Folkman, S., & Lazarus, R.S. (1985). If it changes it must be a process: study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology, 48*(1), 150-170.
Friedman, D., Holmbeck, G.N., Jandasek, B., Zuckerman, J., & Abad, M. (2004). Parent functioning in families of preadolescents with spina bifida: Longitudinal implications for child adjustment. *Journal of Family Psychology, 18*(4), 609-619.
Gendolla, G., & Brinkmann, K. (2005). The role of mood states in self-regulation: Effects on action preference and resource mobilization. *European Psychologist, 10*(3), 187-198.
Glasscoe, C., Lancaster, G.A., Smyth, R.L., & Hill, J. (2007). Parental depression following the early diagnosis of cystic fibrosis: A matched, prospective study. *The Journal of Pediatrics, 150*(2), 185-191.
Grootenhuis, M.A., & Last, B.F. (1997). Predictors of parental emotional adjustment to childhood cancer. *Psycho-Oncology, 6*, 115-128.
Harvey, E., Danforth, J.S., Waszek, W.R., & Eberhardt, T.L. (2001). Validity of the parenting scale for parents of children with attention-deficit/hyperactivity disorder. *Behaviour and Research Therapy, 39*, 731-743.
Hirose, T., & Ueda, R. (1990). Long-tern follow-up study of cerebral palsy children and

coping behaviour of parents. *Journal of Advanced Nursing, 15*(7), 762-770.
Hirtz, D., Thurman, D.J., Gwinn-Hardy, K., Mohamed, M., Chaudhuri, A.R., & Zalutsky, R. (2007). How common are the "common" neurologic disorders? *Neurology, 30*(68), 326-337.
Hodell, E. (2004). Chronic sorrow and depression in parents of children with neural tube defects. *Journal of Neuroscience Nursing, 36*(2), 82-88.
Horowitz, J.A., Bell, M., Trybulski, J., Munro, B.H., Moser, D., Hartz, S.A., McCordic, L., & Sokol, E.S. (2001). Promoting responsiveness between mothers with depressive symptoms and their infants. *Journal of Nursing Scholarship, 33*(4), 323-329.
Jacoby, A., Snape, D., & Baker, G.A. (2005). Epilepsy and social identity: the stigma of chronic neurological disorders. *Lancet Neurology, 4*(3), 171-178.
Jessop, D.J., & Stein, R.E. (1985). Uncertainty and its relation to the psychological and social correlates of chronic illness in children. *Social Science and Medicine, 20*(10), 993-999.
Johnson, J.E., Fieler, V.K., Wlasowicz, G.S., Mitchell, M.L., & Jones, L.S. (1997). The effects of nursing care guided by self-regulation theory on coping with radiation therapy. *Oncology Nursing Forum, 24*(6), 1041-1050.
Johnson, J.E. (1999). Self-regulation theory and coping with physical illness. *Research in Nursing and Health, 22*, 435-448.
Johnson, B. S. (2000). Mothers' perceptions of parenting children with disabilities. *MCN: The American Journal of Maternal/Child Nursing*, *25*(3), 127
Kao, B., Lobatto, D., Grullon, E., Cheas, L., Plante, W., Seifer, R., et al. (2011). Recruiting latino and non-latino families in pediatric research: considerations from a study on childhood disability. *Journal of Pediatric Psychology, 36*(10), 1093-1101.
Karlson, C.W. & Rapoff, M.A. (2008). Attrition in randomized controlled trials for pediatric chronic conditions. *Journal of Pediatric Psychology, 34*(7), 782-793.
Keller, D., & Honig, A.S. (2004). Maternal and paternal stress in families with school aged children with disabilities. *American Journal of Orthopsychiatry, 74*(3), 337-348.
Kohlen, C., Beier, J., & Danzer, G. (2000). They don't leave you on your own: a qualitative study of the home care of chronically ill children. *Pediatric Nursing, 26*(4), 364-371.
Koocher, G.P. (1985). Psychological care of the child cured of cancer. *Pediatric Nursing*, 91-93.
Lazarus, R.S., & Folkman, S. (1984). *Stress, Appraisal, and Coping.* New York: Springer.
Leung, D.W., & Slep, A.M. (2006). Predicting inept discipline: The role of parental depressive symptoms, anger, and attributions. *Journal of Consulting and Clinical Psychology, 74*(3), 524-534.
Low, S., & Stocker, C. (2005). Family functioning and children's adjustment: Associations among parents' depressed mood, marital hostility, parent-child hostility and children's adjustment. *Journal of Family Psychology, 19*(3), 394-403. doi: 10.1037/0893-3200.19.3.394
Lv, R., Wu, L., Jin, L., Lu, Q., Wang, M., Qu, Y., et al. (2009). Depression, anxiety and quality of life in parents of children with epilepsy. *Acta Neurologica Scandinavica, 120*(5), 335-341.

Mah, J.K., Thannhauser, J.E., McNeil, D.A. & Dewey, D. (2008). Being the lifeline: the parent experience of caring for a child with neuromuscular disease on home mechanical ventilation. *Neuromuscular Disorders, 18*(12), 983-988.

McNelis, A.M., Buelow, J., Myers, J., & Johnson, E.A. (2007). Concerns and needs of children with epilepsy and their parents. Clinical Nurse Specialist: The Journal of Advanced Nursing Practice, 21(4), 195-202.

Melnyk, B.M. (1994). Coping with unplanned childhood hospitalization: effects of informational interventions on mothers and children. *Nursing Research, 43*(1), 50-55. doi: 10.1097/00006199-199401000-00011

Melnyk, B.M. (1995). Parental coping with childhood hospitalization: A theoretical framework to guide research and clinical interventions. *Maternal Child-Nursing Journal, 23*(4), 123-131.

Melnyk, B.M., Alpert-Gillis, L.J., Hensel, P.B., Cable-Beiling, R.C., & Rubenstein, J.S. (1997). Helping mothers cope with a critically ill child: A pilot test of the COPE intervention. *Research in Nursing & Health, 20*, 3-14.

Melnyk, B.M., & Alpert-Gillis, L.J. (1998). The COPE Program: A strategy to improve outcomes of critically ill young children and their parents. *Pediatric Nursing, 24*(6), 521-539.

Melnyk, B.M. (2000). Intervention studies involving parents of hospitalized young children: An analysis of the past and future recommendations. *Journal of Pediatric Nursing: Nursing Care of Children and Families, 15*(1), 4-13. doi: 10.1053/jpdn.2000.0150004

Melnyk, B.M., Alpert-Gillis, L., Feinstein, N.F., Fairbanks, E., Schultz-Czarniak, J., Hust, D., Sherman, L., LeMoine, C., Moldenhauer, Z., Small, L., Bender, N., Sinkin, R.A. (2001a). Improving cognitive development of low-birth-weight premature infants with the COPE program: a pilot study of the benefit of early NICU intervention with mothers. *Research in Nursing & Health. 24*(5):373-89. doi: 10.1002/nur.1038

Melnyk, B.M., Feinstein,N.F., Moldenhouer, Z., & Small, L. (2001b). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing, 27*(6), 548-558.

Melnyk, B.M., Alpert-Gillis, L., Feinstein, N., Crean, H., Johnson, J., Fairbanks, E., S Small, L., Rubenstein, J., Slota, M., & Corbo-Richert, B. (2004). Creating opportunities for parent empowerment: Program effects on the mental health/coping outcomes of critically ill young children and their mothers. *Pediatrics, 113*(6), e597-e607. doi: 10.1542/peds.113.6.e597

Melnyk, B.M., Feinstein, N.F., Alpert-Gillis, L., Fairbanks, E., Crean, H. F., Sinkin, R.A.. et al. (2006). Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics, 118*(5), e1414-e1427. doi: 10.1542/peds.2005-2580

Mishel, M.H., & Braden, C.J. (1988). Finding meaning: antecedents of uncertainty in illness. *Nursing Research, 37*(2), 98-104. doi: 10.1097/00006199-198803000-00009

Mishel, M.H. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research, 17*, 269-294.

Mitchell, W.G. (1995). Long-term prognosis for children with epilepsy. *Current Problems in Pediatrics, 25*(3), 113-120. doi: 10.1016/S0045-9380(06)80005-8

Modi, A.C., Ingerski, L.M., Rausch, J.R., & Glauser, T.A. (2011). Treatment factors affecting longitudinal quality of life in new onset pediatric epilepsy. *Journal of Pediatric Psychology, 36*(4), 466-475. doi: 10.1093/jpepsy/jsq114

Monsen, R.B. (1999). Mothers' experiences of living worried when parenting children with spina bifida. *Journal of Pediatric Nursing, 14*(3), 157-163. doi: 10.1016/S0882-5963(99)80004-9

Moore, I.M., Challinor, J., Pasvogel, A., Matthay, K., Hutter, J., & Kaemingk, K. (2003). Behavioral adjustment of children and adolescents with cancer: teacher, parent, and self-report. *Oncology Nursing Forum, 30*(5), 84-91.

Mu, P., & Tomlinson, P. (1997). Parental experience and meaning construction during a pediatric health crisis. *Western Journal of Nursing Research, 19*(5), 608-636. doi: 10.1177/019394599701900504

Mu, P., Wong, T., Chang, K., & Kwan, S. (2001). Predictors of maternal depression for families having a child with epilepsy. *Journal of Nursing Research, 9*(4), 116-125. doi: 10.1097/01.JNR.0000347569.07435.73

Mu, P. (2005). Paternal reactions to a child with epilepsy: uncertainty, coping strategies, and depression. *Journal of Advanced Nursing, 49*(4), 367-376. doi: 10.1111/j.1365-2648.2004.03300.x

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*, 273-282. doi: 10.1016/j.ijnurstu.2004.07.002

Mu, P.F. (2008). Transition experience of parents caring for children with epilepsy: a phenomenological study. *International Journal of Nursing Studies, 45*(4), 543-551. doi: 10.1016/j.ijnurstu.2006.10.009

Mu, P.F., & Chang, K.P. (2010). The effectiveness of a programme of enhancing resiliency by reducing family boundary ambiguity among children with epilepsy. *Journal of Clinical Nursing, 19*, 1443-1453. doi: 10.1111/j.1365-2702.2009.03075.x

Mullins, L.L., Chaney, J.M., Balderson, B., & Hommel, K.A. (2000). The relationship of illness uncertainty, illness intrusiveness, and asthma severity to depression in young adults with long-standing asthma. *International Journal of Rehabilitation an Health, 5*(3), 177-186. doi: 10.1093/jpepsy/jsm044

National Institutes of Health. (2007). Retrieved March 21, 2007 from: http://www.nih.gov/about/.

Nerenz, D.R., & Leventhal, H. (1983). *Self-regulation theory in chronic illness.* In Burish, T.G., & Bradley, L.A. (Eds.), Coping with Chronic Disease: Research and Applications (pp. 13-37). New York: Academic Press.

Newberry, A., Sherwood, P., Hricik, A., Bradley, S., Kuo, J., Crago, E., et al. (2010). Understanding recruitment and retention in neurological research. *Journal of Neuroscience Nursing, 42*(1), 47-57. doi: 10.1097/JNN.0b013e3181c1fdd9

Oostrom, K.J., Schouten, A., Kruitwagen, C.L., Peters, A.C., & Jennekens-Schinkel, A. (2001). Parents' perceptions of adversity introduced by upheaval and uncertainty at the onset of childhood epilepsy. *Epilepsia, 42*(11), 1452-1460. doi: 10.1046/j.1528-1157.2001.14201.x

Patel, M.X., Doku, V., & Tennakoon, L. (2003). Challenges in recruitment of research participants. *Advances in Psychiatric Treatment, 9*, 229-238. doi: 10.1192/apt.9.3.229

Reynolds, C. R., & Kamphaus, R. W. (1992). *Behavior assessment system for children (BASC).* Circles Pines: AGS.

Reynolds, C.R., & Kamphaus, R.W. (2002). *The Clinicians Guide to the Behavior Assessment System for Children (BASC).* New York: Guilford Press.

Rodenburg, R., Meijer, A.M., Dekovic, M., & Aldencamp, A. (2006). Family predictors of psychopathology in children with epilepsy. *Epilepsia, 47*(3), 601-614. doi: 10.1111/j.1528-1167.2006.00475.x

Rodenburg, R., Meijer, A.M., Dekovic, M., Aldenkamp, A.P. (2007). Parents of children with enduring epilepsy: predictors of parenting stress and parenting. *Epilepsy & Behavior. 11*(2):197-207. doi: 10.1016/j.yebeh.2007.05.001

Rodenburg, R., Wagner, J.L., Austin, J.K., Kerr, M., & Dunn, D.W. (2011). Psychosocial issues for children with epilepsy. *Epilepsy & Behavior, 22*, 47-54. doi: 10.1016/j.yebeh.2011.04.063

Rutter, M., Graham, P.J., & Yule, W. (1970). A Neuropsychiatric Study in Childhood. Heinemann Medical: Philadelphia.

Sahler, O.J., Fairclough, D.L., Phipps, S., Mulhern, R.K., Dolgin, M.J., Noll, R.B., Katz, E.R., Varni, J.W., Copeland, D.R., & Butler, R.W. (2005). Using problem-solving skills training to reduce negative affectivity in mothers of children with newly diagnosed cancer: Report of a multisite randomized trial. *Journal of Consulting and Clinical Psychology, 73*(2), 272-283. doi: 10.1037/0022-006X.73.2.272

Sample Power. (2007). Chicago: SPSS, Inc.

Shackelton, D.P., Kastelejin-Nolst Trenite, D.G., de Craen, A.J., Vandenbroucke, J.P., & Westendorp, R.G. (2003). Living with epilepsy; long-term prognosis and psychosocial outcomes. *Neurology, 61*, 64-70. doi: 10.1212/01.WNL.0000073543.63457.0A

Sharkey, T. (1995). The effects of uncertainty in families with children who are chronically ill. *Home Healthcare Nurse, 13*(4), 37-42. doi: 10.1097/00004045-199507000-00006

Shatla, R., Sayyah, H., Azzam, H., and Elsayed, R.M. (2011). Correlates of parental stress and psychopathology in pediatric epilepsy. *Annals of Indian Academy of Neurology, 14*(4), 252-256.

Sherman, E.M., Griffiths, S.Y., Akdag, S., Connolly, M.B., Slick, D.J., & Wiebe, S. (2008). Sociodemographic correlates of health-related quality of life in pediatric epilepsy. *Epilepsy & Behavior, 12*(1), 96-101. doi: 10.1016/j.yebeh.2007.07.009

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 of Society of Pediatric Nurses, 7*(2), 71-80. doi: 10.1111/j.1744-6155.2002.tb00153.x

Shore, C.P., Austin, J.K., & Dunn, D.W. (2004). Maternal adaptation to a child's epilepsy. Epilepsy & Behavior, 5(4), 557-568. doi: 10.1016/j.yebeh.2004.04.015

Sillanpaa, M., Haataja, L., & Shinnar, S. (2004). Perceived impact of childhood-onset epilepsy on quality of life as an adult. *Epilepsia. 45*(8):971-7. doi: 10.1111/j.0013-9580.2004.44203.x

Snead, K., Ackerson, J., Bailey, K., Schmitt, M.M., Madan-Swain, A., & Martin, R.C. (2004). Taking charge of epilepsy: the development of a structured psychoeducational group intervention for adolescents with epilepsy and their parents. *Epilepsy & Behavior, 5*, 547-556. doi: 10.1016/j.yebeh.2004.04.012

Spielberger, C.D. (1983). *State-Trait Anxiety Inventory.* Redwood City: Mind Garden.

Sterken, D.J. (1996). Uncertainty and coping in fathers of children with cancer. *Journal of*

Pediatric Oncology Nursing, 13(2), 81-88. doi: 10.1177/104345429601300206

Stewart, J.L., & Mishel, M.H. (2000). Uncertainty in childhood illness: a synthesis of the parent and child literature. *Scholarly Inquiry for Nursing Practice: An International Journal, 14*(4), 299-319.

Thornton, N., Hamiwka, L., Sherman, E., Tse, E., Blackman, M., & Wirrell, E. (2008). Family function in cognitively normal children with epilepsy; impact on competence and problem behaviors. *Epilepsy & Behavior, 12*(1), 90-95. doi: 10.1016/j.yebeh.2007.07.008

Tieffenberg, J.A., Wood, E.I., Alonso, A., Tossutti, M.S., & Vicente, M.F. (2000). A randomized field trial of ACINDES: A child-centered training model for children with chronic illnesses (asthma and epilepsy). *Journal of Urban Health, 77*(2), 280-297. doi: 10.1007/BF02390539

Tzoufi, M., Mantas, C., Pappa, S., Kateri, M., Hyphantis, T., Pavlou, M., Mavreas, V., & Siamopoulou-Mavridou, A. (2005). The impact of childhood chronic neurological disease on Greek families. *Child: Care, Health, & Development, 31*(1), 109-115. doi: 10.1111/j.1365-2214.2005.00492.x

VanderVeer, A.H. (1949). The psychopathology of physical illness and hospital residence. *Quarterly Journal of Child Behavior, 1,* 55-79.

Vessey, J.A. (2003). Children's psychological responses to hospitalization. *Annual Review of Nursing Research, 21*, 173-201.

Wade, S.L., Carey, J., & Wolfe, C.R. (2006). An online family intervention to reduce parental stress following pediatric brain injury. *Journal of Consulting and Clinical Psychology, 74*(3), 445-454. doi: 10.1037/0022-006x.74.3.445

Wagner, J.L., Sample, P.L., Ferguson, P.L., Pickelsimer, E.E., Smith, G.M., & Selassie, A.W. (2009). The impact of pediatric epilepsy: voices from a focus group and implications for public policy change. *Epilepsy & Behavior, 16*, 161-165. doi: 10.1016/j.yebeh.2009.07.008

Williams, J., Steel, C., Sharp, G.B., DelosReyes, E., Phillips, T., Bates, S., Lange, B., & Griebel, M.L. (2003). Parental anxiety and quality of life in children with epilepsy. *Epilepsy & Behavior, 4*, 483-486. doi: 10.1016/S1525-5050(03)00159-8

Wirrell, E.C., Wood, L., Hamiwka, L.D., and Sherman, E.M. (2008). Parenting stress in mothers of children with intractable epilepsy. *Epilepsy & Behavior, 13*, 169-173. doi: 10.1016/j.yeeh.2008.02.011

Yong, L., Chengye, J., & Jiong, Q. (2006). Factors affecting the quality of life in childhood epilepsy in China. *Acta Neurologica Scandinavica, 113*(3), 167-173. doi: 10.1111/j.1600-0404.2005.00567.x

Zimmerman, B.J. (2000). *Attaining self-regulation: a social cognitive perspective*. In Boekaerts, M., Pintrich, P.R., & Zeidner, M. (Eds.), Handbook of Self-Regulation (pp.13-39). Boston: Academic Press. doi: 10.1016/j.bbr.2011.03.031

APPENDIX A

Institutional Review Board Approvals

Boston College

Boston Children's Hospital

BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0948

IRB Protocol Number: 08.309.01

DATE: May 29, 2008

TO: Duffy, Lisa

FROM: Institutional Review Board – Office for Research Protections

RE: COPE Intervention For Families Of Children With Epilepsy

Notice of IRB Review and Approval
Expedited Review as per Title 45 CFR Part 46.110, FR 60366, FR, # 7

The project identified above has been reviewed by the Boston College Institutional Review Board (IRB) for the Protection of Human Subjects in Research using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following standard conditions:

1. You are approved to conduct this research only during the period of approval cited below;
2. You will conduct the research according to the plans and protocol submitted (approved copy enclosed);
3. You will immediately inform the Office for Research Protections (ORP) of any injuries or adverse research events involving subjects;
4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the informed consent documents that have the IRB approval dates stamped on them (approved copies enclosed).
6. You will give each research subject a copy of the informed consent document;
7. You may enroll up to 88 participants.
8. **If your research is anticipated to continue beyond the IRB approval dates, you must submit a Continuing Review Request to the IRB approximately 60 days prior to the**

BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0498

IRB Protocol Number: 08.309.02

DATE: April 21, 2009

TO: Lisa Duffy

CC: Judith Vessey

FROM: Institutional Review Board – Office for Research Protections

RE: COPE Intervention for Parents of Children with Epilepsy

Notice of IRB Review and Approval-Continuing Review
Expedited Review as per Title 45 CFR Part 46.110, FR 60366, FR, # 7

The project identified above has been reviewed by the Boston College Institutional Review Board (IRB) for the Protection of Human Subjects in Research using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

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1. You are approved to conduct this research only during the period of approval cited below;
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4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the informed consent documents that have the IRB approval dates stamped on them (approved copies enclosed);
6. You will give each research subject a copy of the informed consent document;
7. You may enroll up to 88 participants.

BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0498

IRB Protocol Number: 08.309.03B

DATE: February 16, 2010

TO: Lisa Duffy

CC: Judy Vessey

FROM: Office for Research Protections

RE: COPE Intervention for Parents of Children with Epilepsy

Notice of IRB Review and Approval-Continuing Review
Expedited Review as per Title 45 CFR Part 46.110, FR 60366, FR, # 7

The project identified above has been reviewed by the Boston College Institutional Review Board (IRB) for the Protection of Human Subjects in Research using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following standard conditions:

1. You are approved to conduct this research only during the period of approval cited below;
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3. You will immediately inform the Office for Research Protections (ORP) of any injuries or adverse research events involving subjects;
4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the informed consent documents that have the IRB approval dates stamped on them (approved copies enclosed);
6. You will give each research subject a copy of the informed consent document;
7. You may enroll up to 88 participants.

Children's Hospital Boston

Clinical Investigation Office
333 Longwood Avenue, 4th floor
phone 617-355-7052 | *fax* 617-730-0226

To: Lisa Duffy, PhD(c), CPNP, CNRN

From: Anne Sarco, MPH, IRB Administrator
Committee on Clinical Investigation

Date: April 29, 2008

Re: NOTICE OF EXPEDITED APPROVAL
IRB Approval Date: 4/28/08
IRB Activation/Release Date: 4/28/08
IRB Expiration Date: 2/27/09

Protocol Number: X08-04-0206

Protocol Title: COPE INTERVENTION FOR PARENTS OF CHILDREN WITH EPILEPSY

The Committee on Clinical Investigation has approved the above referenced protocol through expedited review procedures. We are now able to release this approval to you since you have adequately responded to the Committee's questions and concerns.

Risks were determined to be minimal with potential for direct benefit.

The Committee has determined that only one parent/guardian is required to provide permission for their child to participate in this study.

Assent is not required as subjects are too young to understand the research and its ramifications.

Please note that Sandra Mott has been removed from the Children's Hospital protocol because this protocol is being reviewed by Dr. Mott's own institution's IRB. It is not necessary for her to be listed on both protocols.

The approved consent form is available on-line through the CHB Informed Consent Library. To obtain the consent form, please go to http://chbcfapps/research/consents. The ICLibrary should be accessed each time you need a consent form to ensure that the current version of the consent is always used. Do not store the consent forms on your computer or make copies for future use. Note that the activation/expiration date on the consent form can only be changed or modified by the staff of the Clinical Investigation Office. Please also note that subjects cannot be enrolled in a study if the consent form has expired. A copy of the signed consent should be kept in your files. It is our understanding that consent forms will be stored in the research record. The subject/family must also be given a signed copy.

The occurrence of unexpected or serious adverse events should promptly be reported to this office. Any revisions, amendments, or changes to the protocol require prior Committee approval. The Committee has asked this office to notify investigators that clinical investigation protocol files are subject to audits at some future time.

cc: Eileen Sporing, MSN, RN
Kristen Graham, BSN

Children's Hospital Boston
Clinical Investigation Office
333 Longwood Avenue, 4th floor
phone 617-355-7052 | *fax* 617-730-0226

To: Lisa Duffy, PhD
Principal Investigator

Date: March 19, 2009

Re: **AMENDMENT - NOTICE OF EXPEDITED APPROVAL**
IRB Amendment Approval Date: 03/19/2009
IRB Protocol Expiration Date: 01/20/2010

Protocol Number: X08-04-0206

Protocol Title: COPE INTERVENTION FOR PARENTS OF CHILDREN WITH EPILEPSY

The Committee on Clinical Investigation has granted approval, through expedited review procedures, for the changes referenced in the amendment form. The following modifications have been reviewed and approved:

- Current inclusion criteria have been modified to include children with a neurological diagnosis.
- A Visa gift card of $25.00 will be provided for each participant each time they complete a set of questionnaires.
- Carole Atkinson has been added to the study staff.

The approved consent form is available on-line through the CHB Informed Consent Library. To obtain the consent form, please go to http://chbcfapps/research/consents. The ICLibrary should be accessed each time you need a consent form to ensure that the current version of the consent is always used. Do not store the consent forms on your computer or make copies for future use. Note that the activation/expiration date on the consent form can only be changed or modified by the staff of the Clinical Investigation Office. Please also note that subjects cannot be enrolled in a study if the consent form has expired. A signed copy of the consent should be kept in your files. The subject/family must also be given a signed copy.

The occurrence of unanticipated problems should promptly be reported to this office. Any revisions, amendments, or changes to the protocol require prior Committee approval. The Committee has asked this office to notify investigators that clinical investigation protocol files are subject to audits at some future time.

Sincerely,

Elizabeth Carroll, IRB Administrator
Committee on Clinical Investigation

Children's Hospital Boston
Office of Clinical Investigation
300 Longwood Avenue
Boston, MA 02115
phone 617-355-7052 | *fax* 617-730-0226

To: Lisa Duffy, PhD, CPNP-PC, CNRN

Date: 11/16/2010

Re: **NOTICE OF EXPEDITED CONTINUING APPROVAL**
APPROVAL DATE: 11/12/2010
EXPIRATION DATE: 11/11/2011

PROTOCOL NUMBER X08-04-0206

PROTOCOL TITLE COPE INTERVENTION FOR PARENTS OF CHILDREN WITH EPILEPSY

The Committee on Clinical Investigation has approved the continuing renewal above referenced protocol through expedited review procedures.

The following modifications have been reviewed and approved as part of this continuing renewal:

- Addition of Tracy Matviya, BSN, RN to study staff

The approved consent form is available on-line through the CHB Informed Consent Library. To obtain the consent form, please go to http://chbcfapps/research/consents. The ICLibrary should be accessed each time you need a consent form to ensure that the current version of the consent is always used. Do not store the consent forms on your computer or make copies for future use. Note that the activation/expiration date on the consent form can only be changed or modified by the staff of the Clinical Investigation Office. Please also note that subjects cannot be enrolled in a study if the consent form has expired. A copy of the consent should be kept in your files. The subject/family should also be given a signed copy.

The occurrence of unanticipated problems should promptly be reported to this office. Any revisions, amendments, or changes to the protocol require prior Committee approval.

The Committee has asked this office to notify investigators that clinical investigation protocol files are subject to audits at some future time.

Sincerely,

Ashley Pysczynski
For the Committee on Clinical Investigation

APPENDIX B

Approved Study Materials

We are currently enrolling participants in a research study

Research Study Title:
Creating Opportunities for Parent Empowerment (COPE) for parents of children with a neurological condition

What is the purpose of the study?
The purpose of this research study is to determine if an intervention can teach parents of children with a neurological condition learn how to help their child cope with having a chronic condition necessitating periodic hospitalization.

Who can participate?
You can participate in this study if:

- You have a child between the ages of 2-6 years old who has a neurological condition
- Your child has either an acute or chronic condition
- Your child will be admitted to the Children's Hospital Boston inpatient neuroscience unit (CHB-INU)
- You have graduated high school and can read English
- You have access to a cellular or home telephone

Where is the study being conducted?
The first part of the study will be conducted at Children's Hospital Boston. For the second part of the study you will be asked to complete some activities with your child once you are home from the hospital.

What do I have to do if I'm in the study?
If you are in this study you will be asked to read and listen to information about how to help your child cope with being in the hospital. You will also be asked to play with your child to help teach them to express their feelings about being sick and in the hospital.

What is the time commitment for the study?
You will be asked to participate in 3 phases of this study, which will take place over 12-14 weeks. The first 2 phases will take approximately 10-15minutes. The third phase involves activities for you and your child to complete together on an ongoing basis. The time for the third phase will depend on how helpful the activity is for you and your child.

At 4 times during the study, you will be asked to complete a series of questionnaires. It will take approximately 30-45 each time to complete the questionnaires.

What are the benefits of the study?
You and your children may benefit from this study as you learn how to help your child cope with having epilepsy. The knowledge gained from this study will also help nurses be better able to care for children with epilepsy and their families.

What will I receive from participating?
You will be asked to complete 3 sets of questionnaires during this study. Each time you complete a set of questionnaires, you will receive a $25 gift card.

This research is being conducted by:
Lisa Duffy PhD(c), CPNP
Pediatric Nurse Practitioner
Children's Hospital Boston

For additional information regarding this study, please contact:
Lisa Duffy PhD(c), CPNP
617-355-8096 or 617-355-6363 page# 5052
Lisa.duffy@childrens.harvard.edu

Creating Opportunities for Parent Empowerment (COPE)

The COPE intervention materials in this study were utilized with direct permission from the original author, Dr. Bernadette Melnyk. The COPE program was tested in a series of research studies funded by the National Institute of Nursing Research (NINR). The information for the initial R01 grant is included below.

Title: Coping with Critically Ill Children: An Intervention
Author: Dr. Bernadette Melnyk
Year: 1997
Grant Number: 1R01NR004174-01A2

SELF-EVALUATION QUESTIONNAIRE

STAI Form Y-2

Name_____ Date_____

DIRECTIONS

A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate you *generally* feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
21. I feel pleasant	1	2	3	
22. I feel nervous and restless	1	2	3	
23. I feel satisfied with myself	1	2	3	
24. I wish I could be as happy as others seem to be	1	2	3	
25. I feel like a failure	1	2	3	
26. I feel rested	1	2	3	
27. I am "calm, cool, and collected"	1	2	3	
28. I feel that difficulties are piling up so that I cannot overcome them	1	2	3	
29. I worry too much over something that really doesn't matter	1	2	3	
30. I am happy	1	2	3	
31. I have disturbing thoughts	1	2	3	
32. I lack self-confidence	1	2	3	
33. I feel secure	1	2	3	
34. I make decisions easily	1	2	3	
35. I feel inadequate	1	2	3	
36. I am content	1	2	3	
37. Some unimportant thought runs through my mind and bothers me	1	2	3	
38. I take disappointments so keenly that I can't put them out of my mind	1	2	3	
39. I am a steady person	1	2	3	
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	1	2	3	

BDI®-II

Date:

Name: _____ Marital Status: _____ Age: _____ Sex: _____

Occupation: _____ Education: _____

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness

0 I do not feel sad.
1 I feel sad much of the time.
2 I am sad all the time.
3 I am so sad or unhappy that I can't stand it.

2. Pessimism

0 I am not discouraged about my future.
1 I feel more discouraged about my future than I used to be.
2 I do not expect things to work out for me.
3 I feel my future is hopeless and will only get worse.

3. Past Failure

0 I do not feel like a failure.
1 I have failed more than I should have.
2 As I look back, I see a lot of failures.
3 I feel I am a total failure as a person.

4. Loss of Pleasure

0 I get as much pleasure as I ever did from the things I enjoy.
1 I don't enjoy things as much as I used to.
2 I get very little pleasure from the things I used to enjoy.
3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

0 I don't feel particularly guilty.
1 I feel guilty over many things I have done or should have done.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.

6. Punishment Feelings

0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.

7. Self-Dislike

0 I feel the same about myself as ever.
1 I have lost confidence in myself.
2 I am disappointed in myself.
3 I dislike myself.

8. Self-Criticalness

0 I don't criticize or blame myself more than usual.
1 I am more critical of myself than I used to be.
2 I criticize myself for all of my faults.
3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

10. Crying

0 I don't cry anymore than I used to.
1 I cry more than I used to.
2 I cry over every little thing.
3 I feel like crying, but I can't.

11. Agitation

0 I am no more restless or wound up than usual.

1 I feel more restless or wound up than usual.

2 I am so restless or agitated that it's hard to stay still.

3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0 I have not lost interest in other people or activities.

1 I am less interested in other people or things than before.

2 I have lost most of my interest in other people or things.

3 It's hard to get interested in anything.

13. Indecisiveness

0 I make decisions about as well as ever.

1 I find it more difficult to make decisions than usual.

2 I have much greater difficulty in making decisions than I used to.

3 I have trouble making any decisions.

14. Worthlessness

0 I do not feel I am worthless.

1 I don't consider myself as worthwhile and useful as I used to.

2 I feel more worthless as compared to other people.

3 I feel utterly worthless.

15. Loss of Energy

0 I have as much energy as ever.

1 I have less energy than I used to have.

2 I don't have enough energy to do very much.

3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

0 I have not experienced any change in my sleeping pattern.

1a I sleep somewhat more than usual.

1b I sleep somewhat less than usual.

2a I sleep a lot more than usual.

2b I sleep a lot less than usual.

3a I sleep most of the day.

3b I wake up 1–2 hours early and can't get back to sleep.

17. Irritability

0 I am no more irritable than usual.

1 I am more irritable than usual.

2 I am much more irritable than usual.

3 I am irritable all the time.

18. Changes in Appetite

0 I have not experienced any change in my appetite.

1a My appetite is somewhat less than usual.

1b My appetite is somewhat greater than usual.

2a My appetite is much less than before.

2b My appetite is much greater than usual.

3a I have no appetite at all.

3b I crave food all the time.

19. Concentration Difficulty

0 I can concentrate as well as ever.

1 I can't concentrate as well as usual.

2 It's hard to keep my mind on anything for very long.

3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

0 I am no more tired or fatigued than usual.

1 I get more tired or fatigued more easily than usual.

2 I am too tired or fatigued to do a lot of the things I used to do.

3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

0 I have not noticed any recent change in my interest in sex.

1 I am less interested in sex than I used to be.

2 I am much less interested in sex now.

3 I have lost interest in sex completely.

_____ Subtotal Page 2

_____ Subtotal Page 1

_____ Total Score

Parental Beliefs Scale for Hospitalized Children
(Bernadette Mazurek Melnyk, 1991)

Below are 20 statements that relate to you and your child's hospitalization. Hospital experiences differ for every parent. There are some parents who are not so sure about their children's needs and how they can best meet them while they are in the hospital, while other parents are more sure about how to help their children through this experience. Keep in mind that your confidence (how sure you are) about helping your child deal with being in the hospital may be different from the confidence you usually have in dealing with your child at home. There are no right or wrong answers to the following statements or how you feel while your child is in the hospital. Please circle the number that best describes your agreement or disagreement with each statement.

a

1. I know what changes in behavior to expect in my child while he (or she) is in hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

2. I do NOT know what my child's emotions will be like while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

3. I am sure that what I do for my child will be what is best to help him (or her) deal with being in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

4. I am NOT sure about how my child will behave when painful things are done to him (or her) in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

5. I know what changes in behavior to expect in my child AFTER he (or she) leaves the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

6. I am NOT sure about what I can do to best help my child get through the painful things that are done to him (or her) in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

7. I do NOT understand why my child is behaving the way he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

8. I am sure I can meet all of my child's emotional needs while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

9. I do NOT know what my child will think about the things that are done to him (or her) in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

10. I am clear about the things that I can do to best help my child deal with being in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

11. I am NOT sure how my child will act towards me while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

12. I know how my emotions will affect my child while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

13. No matter how my child behaves while he (or she) is in the hospital, I am sure I will be able to handle it.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree	Agree	Strongly Disagree

Or Disagree

14. I am NOT sure of what things I can do to best help my child deal with his (or her) illness or injury.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

15. I am NOT sure about what I can do to make my child feel most secure while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

16. I feel confident in telling the nurses and doctors about what will best help my child while he (or she) is in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

17. I am NOT sure about how my child will behave when things frighten him (or her) in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

18. I do NOT know what I can do to best help my child deal with frightening things in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

19. I feel confident in asking the doctors and nurses questions about my child's illness or injury.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

20. I know how to prepare my child for things that will frighten or hurt him (or her) in the hospital.

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree Or Disagree	Agree	Strongly Disagree

BASC

Behavior Assessment System for Children

Parent Feedback Report

Parent Rating Scales

Cecil R. Reynolds, Ph.D., and Randy W. Kamphaus, Ph.D.

Child's Name _____ Age _____

Parent's Name _____ Test Date _____

Clinician's Name _____ Clinician's Number (___) _____

What is the BASC?

The BASC *(Behavior Assessment System for Children)* is a well-known system used by psychologists, education professionals, physicians, and other clinicians to learn about a child's behavior and feelings. Developed by prominent experts on child behavior, the BASC has several components that gather information from parents, teachers, and the child. This information focuses on both strengths and weaknesses of the child's behavior and feelings, so that your child's positive features do not go unnoticed while potential problem areas are being explored. The purpose of this report is to help you understand the information that has been gathered about your child from the Parent Rating Scales.

Why are parent ratings important?

Parents tend to know their child better than anyone else. They see their child behave in a variety of settings over a long period of time. As a result, they can describe specific features of their child's behavior. Thus, parent ratings help the psychologist or clinician form a more complete and accurate picture of the child, identify problem behaviors and competencies, and develop a treatment plan if needed.

What is the BASC Parent Rating Scales?

The BASC Parent Rating Scales (PRS) consists of about 150 statements describing positive and negative behaviors. The parent or caregiver indicates how often the child displays each of these behaviors, answering *Never, Sometimes, Often,* or *Almost Always.* These statements are grouped into 10 to 12 scales, with each scale relating to a specific area of behavior. The answers to the statements within a scale ar added up to give a total score for the scale. These scores tel the psychologist or clinician about the child's pattern of behaviors. Usually, the response to an individual behavior statement is far less important than the pattern of scale scores.

How did I rate my child?

The best way to interpret your responses is to compar your scores with the scores obtained from a national sampl of hundreds of parents who rated children the same age a yours. To do this, we report the scale scores so that they hav an average of 50. If your child has a score of 50 on a scal then your rating of your child's behavior in this area is average for children of this age. Scores from 41 through 59 are in the average range, and about two out of three children have scores within this range.

The following pages show a table and chart summarizin your child's scores. The table shows your child's score in eac behavior area, along with a brief description of how a chil with that score may behave. The chart provides an overviev of your child's scores in all behavior areas. In both the table and the chart, scores in the shaded area may indicat problems that your child is experiencing.

A score in a shaded area of the table or chart does not necessarily mean that your child has a problem that is unusual or that requires treatment. Such a conclusion mus be made by a psychologist or other qualified clinician, or by a treatment team.

CLINICAL SCALES	**HYPERACTIVITY**	Score ___ Indicates typical levels of activity displayed by the average child of this age.	Score ___ Indicates problematic levels of activity; child may display or engage in: ■ Being restless ■ Interrupting others ■ Impatience
	AGGRESSION	Score ___ Indicates typical levels of aggression displayed by the average child of this age.	Score ___ Indicates problematic levels of aggression; child may display or engage in: ■ Threats ■ Hitting others ■ Tendency to argue
	CONDUCT PROBLEMS (Ages 6-18 only)	Score ___ Indicates typical levels of conduct problems displayed by the average child of this age.	Score ___ Indicates problematic levels of conduct problems; child may engage in: ■ Lying ■ Alcohol/drug use ■ Stealing
	ANXIETY	Score ___ Indicates typical levels of anxiety displayed by the average child of this age.	Score ___ Indicates problematic levels of anxiety; child may display: ■ Worrying ■ Irrational fears ■ Nervousness
	DEPRESSION	Score ___ Indicates typical levels of depression displayed by the average child of this age.	Score ___ Indicates problematic levels of depression; child may display or complain of: ■ Sadness ■ Being overwhelmed ■ Depressed mood
	SOMATIZATION	Score ___ Indicates typical levels of somatization displayed by the average child of this age.	Score ___ Indicates problematic levels of somatization; child may display or complain of: ■ Headaches ■ Difficulty breathing ■ Stomachaches
	ATYPICALITY	Score ___ Indicates typical levels of atypicality displayed by the average child of this age.	Score ___ Indicates problematic levels of atypicality; child may display or engage in: ■ Being easily sidetracked ■ Unusual or repetitive ■ Self-injurious behaviors thoughts
	WITHDRAWAL	Score ___ Indicates typical levels of withdrawal displayed by the average child of this age.	Score ___ Indicates problematic levels of withdrawal; child may display or report: ■ Shyness ■ Avoidance ■ Reluctance to socialize
	ATTENTION PROBLEMS	Score ___ Indicates typical levels of attention problems displayed by the average child of this age.	Score ___ Indicates problematic levels of paying attention; child may display: ■ Giving up easily ■ Inability to listen ■ Being distracted closely
ADAPTIVE SCALES		**LOW** (Score: 20-40)	**AVERAGE/HIGH** (Score: 41 or Higher)
	ADAPTABILITY (Ages 2.5-11 only)	Score ___ Indicates problematic levels of adaptability; child may display: ■ Difficulty switching tasks ■ Difficulty adjusting ■ Stubbornness to change	Score ___ Indicates typical levels of adaptability displayed by the average child of this age.
	SOCIAL SKILLS	Score ___ Indicates problematic levels of social skills; child may display: ■ Lack of encouragement ■ Unwillingness to ■ Inappropriate responses volunteer	Score ___ Indicates typical levels of social skills displayed by the average child of this age.
	LEADERSHIP (Ages 6-18 only)	Score ___ Indicates below-average levels of leadership; child may display: ■ Physical inactivity ■ Low involvement in ■ Indecisiveness school clubs	Score ___ Indicates typical levels of leadership displayed by the average child of this age.

APPENDIX C

Consent Form

Why is this research study being conducted; What is its purpose?

The purpose of this research study is to test an educational program designed for parents of children with a neurological or neurosurgical condition called Creating Opportunities for Parent Empowerment (COPE). We are asking you to take part because you have a child who has been diagnosed with a neurological or neurosurgical condition.

Who is conducting this research study, and where is it being conducted?

This study will take place at Children's Hospital Boston. Lisa Duffy PhD(c) is a nurse practitioner at Children's Hospital Boston and will be the Principal Investigator for this study. We expect that about 88 parents will be in this study. This research study is being sponsored by the National Institutes of Health.

How are individuals selected for this research study? How many will participate?

Parents are being selected for this study if they have a child between the ages of 2 and 6 years who has been diagnosed with a neurological or neurosurgical condition. Parents will need to be high school graduates who are able to read and understand English. This is necessary because you will be asked to read materials and complete several questionnaires that exist only in English, and are written at a 10^{th} grade reading level. Parents will also need to have access to a cellular or home telephone, as a nurse will call you at home (by telephone) after your child has been discharged from the hospital.

What do I have to do if I am in this research study?

If you agree to be in this research study, you will be put in one of two groups, an experimental and a control group. After you decide to be in this study, the research assistant will select a random number from a table. The number that is chosen will tell us which group to place you in. Parents in the control group will receive the same care provided by the nursing staff on 9NorthWest. The usual care provided by the nurses on 9NorthWest includes written and verbal information about seizures, medications your child may need to take, and any tests or procedures your child may undergo while in the hospital. All patients discharged from 9NorthWest will receive a phone call from a nurse after they get home to see if you had any problems during your stay or if you have and questions or concerns. Parents in the experimental group, in addition to the care provided by the nursing staff, will also be given additional information about how to help their child cope with being sick and in the hospital. This information will be both written and audiotaped. The additional information will include education about how being in the hospital may affect your child emotionally. The additional information will also teach you ways in which you can play with your child to help him or her learn to cope with being sick. To help your child express their feelings you will be taught how to use play therapy with the use of puppets and a doctor's kit. This study will last for 12 to 14 weeks.

The following table shows you what you will be asked to do during each part of the study:

During admission to the unit	Sign informed consent Complete questionnaires Receive information about the hospital unit
3 days after discharge from hospital	A research assistant will call you at home to review information you were given in the hospital
one week after discharge from hospital	Complete questionnaires mailed to you at home and return (in a self-addressed stamped envelope) to research assistant
4-6 weeks after discharge	Receive workbook in the mail to complete at home with your child
4-6 weeks after final intervention	Complete questionnaires mailed to you at home and return (in a self-addressed stamped envelope) to research assistant

The questionnaires you will complete ask questions about any feelings of anxiety or depression you may have. You will also be asked to answer questions about your child's behavior and how you feel about your parenting skills.

This study includes a control group (people who do not receive the educational program) who will receive the usual care and additional handouts currently provided to parents on this hospital unit. This is done so that we will be able to tell if the additional education teaches parents ways to help their children cope.

What are the risks of this research study? What could go wrong?

Parents may be bothered by the amount of time it takes to complete the questionnaires (approximately 30-45 minutes). Parents may also experience anxiety or depression when answering questions about the health of their child or their parenting skills. If at anytime during the study you experience sadness or anxiety, a member of the research team will help you find someone to talk with if you feel that would be helpful. If a parent has moderate to severe feelings of anxiety or depression during the study, a member of the research team will refer that parent to a mental health professional for additional care. If the anxiety or depression interferes with your participation in the study, you may be asked to leave the study so you may receive the care that you need.

What are the benefits of this research study?

Parents and their children may benefit from this study by learning how to help their child and family live with a neurological condition. Knowledge gained from this study may improve the lives of people living with disabilities.

Nurses may benefit from this study because it may help us to understand what information is most helpful for parents of children with a neurological condition.

Are there costs associated with this research study? Will I receive any payments?

There will be no additional costs to you as a result from participating in this research study.

Three times during this study, you will be asked to fill out a set of questionnaires. Each time you complete a set of questionnaires you will receive a $25 gift card.

What will happen with the information obtained as part of this research study? What about

confidentiality?

Any personal information will be kept in a separate locked file that may only be accessed by the principal investigator for the study, Lisa Duffy. To maintain confidentiality, each questionnaire you complete will be assigned a number. This way, you will not have to put your name on any of the forms. Information or results from the study, not containing your name, may be released to the following:

- Boston College
- The National Institutes of Health

The results of the research study will not be placed in your child's medical record. It will be unlikely that others within the hospital, an insurance company or employer would ever learn of such results

If I do not want to take part in this research study, what are the other choices?

Participation in this research study is voluntary. Choosing not to participate in this study will not interfere with the current or future care your child receives at Children's Hospital.

What are my rights as a research participant?

Taking part in this research study is up to you. You can decide not to take part. Your decision won't change the medical care you get at Children's Hospital now or in the future. There will be no penalty, and you won't lose any benefits you receive now or have a right to receive. If you decide to take part now, you can change your mind and drop out later. We will tell you if we learn new information that could make you change your mind about taking part in this research study.

If you take part in this research study, and want to drop out, you should tell us. We will make sure that you stop the study safely. We will also talk to you about follow-up care, if needed.

It is possible that we will have to ask you to drop out before you finish the study. If this happens, we will tell you why. We will also help arrange other care for you, if needed.

Are there other things I should know about?

The information collected from this study may be used in the future to answer other questions. This information will not include any information that would identify you. Your confidentiality would still be protected.

In the future, we may wish to contact you to talk about your experiences with this research study. You do not have to participate in both parts of the study. If you choose not to be contacted after the study has ended, the care for you and your child will not be changed in any way. If you would be willing to participate in future discussions about this study please initial below.

☐ Yes, I would be willing to be contacted at a future date _____ (date/initial)

☐ No, I do not wish to be contacted after this study is finished

Why would I be taken off the study early?

The researcher may need to end your participation in the study if the study is cancelled by the sponsor. Also, if at any time the researcher thinks that your health or the health of your child is being negatively affected by the study.

What information do I need to know about the Health Insurance Portability and Accountability Act (HIPAA)?

During this research, information about your or your child's health will be collected. In general, under federal law, information about patients is private, but there are exceptions and you should know who will have access to this information and might see it. Researchers may be collecting information about you or your child from medical records. They may also learn things from procedures that are part of the research itself such as tests, office visits, questionnaires and interviews.

The following people will be able to see this information:

- Medical and research staff at Children's Hospital, including people listed on your informed consent.

- Medical staff who are directly involved in your care that is related to the research or arise from it.
- People who oversee, advise or conduct research at Children's Hospital, and people who oversee or evaluate research and care, including the Committee on Clinical Investigation, staff working on quality improvement, and other clinicians and administrative staff of Children's Hospital..
- People from agencies and organizations that provide independent accreditation and oversight of research
- Sponsors or others involved in funding the research
- Nursing faculty at Boston College
- Federal agencies that oversee or review research information.
- Government agencies and sponsors.
- If some law or court requires us to share the information, we would have to follow that law or final ruling

You/your child should be aware that the federal privacy rule does not cover all of these possible uses. This means that once some of the above mentioned users receive your/your child's health information they do not have to follow the same rules. Other laws may or may not protect sharing of private health information. If you have a question about this you may contact the Children's Hospital Privacy Officer at 617-355-5502

There is no set time for destroying this information and no time limit for its use. Researchers continue to analyze data for many years and it is not possible to know when they will be done.

You do not have to sign this form. If the form is not signed, however, you won't be able to participate in the study. Not signing will not affect your care or your child's care at Children's Hospital in any way now or in the future. Also, there will be no penalty or loss of benefits if you choose not to sign and participate.

You or your child also have the right to withdraw from this study at any time. You have the right to end your permission for Children's Hospital to use or share the protected information about you or your child that was collected as part of the research.

Researchers may also continue to use information already collected to protect the integrity of the study. This means that your withdrawal won't make the whole study useless. Once you remove your permission and you or your child is no longer in the study, no more private health information will be collected. If you wish to withdraw you will need to do so in writing. Your investigator will have a form for you to use. If you or your child decide to share private information with anyone not involved in the study, the federal law designed to protect privacy may no longer apply to this information.

Although there are some legal limitations, you or your child have the right to get protected information resulting from this research that relates to your treatment or to payments. This information is available after the study analysis is done. To request the information, please contact the Hospital's Privacy Officer at 617-355-5502. If you have questions, please be sure to ask for answers.

Research at Children's Hospital: Children's Hospital has recently developed a web-based, interactive educational program for parents called "A Parent's Guide to Medical Research." To find out more about research at Children's Hospital, please visit the program at www.researchchildren.org

Children's Hospital is interested in hearing your comments, answering your questions and responding to any concerns regarding clinical research at Children's Hospital. If you would like further information about the type of clinical research performed at the hospital or have suggestions, questions or concerns regarding clinical research you may send an email to cci@childrens.harvard.edu or call 617 355-7052 between the hours of 8:30 and 5:00.

INVESTIGATOR'S AND/OR ASSOCIATE'S STATEMENT:

I have fully explained
to_____[participant/parent/guardian]

the nature and purpose of the above-described procedures and the risks involved in its performance. I have provided the subject/family with the Privacy Rule if requested. I have answered and will answer all questions to the best of my ability. I will inform the participant of any changes in the procedures or the risks and benefits if any should occur during or after the course of the study. I have given a copy of the consent/authorization form to the subject/family.

☒ _____ _____

Date (MM/DD/YEAR) Signature of **Investigator or Associate**

CONSENT/AUTHORIZATION:

***If the child to be involved in this research study is a foster child or a ward of the state please notify the researcher or their staff who is obtaining your consent.**

I understand that I may use the following contact information to reach the appropriate person/office to address any questions or concerns I may have about this study. I know:

I can call … about …	At …	If I have questions or concerns
Investigator: Lisa Duffy PhD(c)	Phone: **617-355-8096** Pager: **617-355-6363 #5052**	▪ General questions about the study ▪ Research-related injuries or emergencies ▪ Any research-related concerns or complaints
Study Contact: Kristen Graham	Phone: **617-355-8096**	▪ General questions about the study ▪ Research-related injuries or emergencies ▪ Any research-related concerns or complaints
Office of Clinical Investigations	Phone: **617-355-7052**	▪ Rights of a research subject ▪ Use of protected health information ▪ Compensation in event of research-related injury ▪ Any research-related concerns or complaints ▪ If investigator/study contact cannot be reached ▪ If I want to speak with someone other than the Investigator, Study Contact or research staff

I have been satisfactorily informed of the above-described procedure with its possible risks and benefits. I have been provided with the applicable Privacy Rule provisions under the Health Insurance Portability and Accountability Act. I give permission for my/my child's participation in this study and for use of the associated protected health information as described above.

I understand that participation in this study is voluntary. If I refuse to participate or choose to drop out of the study at any time, I understand there will be no penalty or loss of benefits to which I am otherwise entitled, and this decision will not affect present or future care by the doctors or the hospital. I am signing this consent form before participating in any research activities. I have been given a copy of this form.

☒ _____ _____

_____

Date (MM/DD/YEAR) Signature of **Parent or Guardian/Adult Participant**

Relationship to child\

WITNESS SIGNATURE REQUIRED BELOW <u>ONLY IF: (check which one applies)</u>

☐ the consent document needs to be read to subject or legal representative **<u>or</u>**

☐ communication impairments limit the subject's ability to clearly express consent **<u>or</u>**

☐ required by sponsor/CCI.

☐ other reason: please specify _____

I confirm that the information in this consent form was accurately explained to, and understood by the subject or legally authorized representative, and that informed consent was given freely.

☒ _____ _____

Date (MM/DD/YEAR) Signature of **Witness**