EVIDENCE-BASED INTERVENTION FOR FAMILIES OF CHILDREN WITH EPILEPSY

By

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Final approval and acceptance of this practice inquiry is contingent upon the candidate’s submission of the final copies of the practice inquiry to the Graduate College.

I hereby certify that I have read this practice inquiry prepared under my direction and recommend that it be accepted as fulfilling the practice inquiry requirement.

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SIGNED: Megan C. Costolo
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The purpose of this paper is to propose an evidence-based intervention guideline to increase effective coping and positive adaptation in families with a preschool age child who has epilepsy. This population was chosen because there is a lack of research regarding interventions for families of preschool age children with epilepsy. Relevant literature was reviewed to summarize the effects of childhood epilepsy on families, and to assess the effectiveness of interventions to improve coping and adaptation in these families. The main stressors caused by epilepsy are knowledge deficits about epilepsy, knowledge deficits about treatments for epilepsy, increased seizure frequency, and emotional disturbances caused by epilepsy. Prior interventions for families of children with epilepsy included psychoeducational programs, support groups, education programs, family counseling groups, and therapeutic alliance. All interventions in the studies reviewed had positive outcomes for families of children with epilepsy. However, psychoeducational programs tended to address all of the common stressors, whereas other interventions did not. This paper provides an evidence-based intervention guideline for families affected by epilepsy. The significance and limitations of the program are discussed, and recommendations for future research in this area are presented.
CHAPTER I: INTRODUCTION TO THE PROBLEM

Introduction

The purpose of this paper is to propose an evidence-based intervention guideline to increase effective coping in families with a preschool age child with epilepsy. This proposed guideline will be based on a literature review summarizing the family stressors associated with caring for a child with epilepsy and interventions aimed at helping these families with coping and adaptation. Chapter one begins with an overview of physical aspects of epilepsy as background for discussion of the difficulties families may have in adapting to the stressor of having a child with epilepsy. The proposed guideline is framed with the Family Stress and Coping model, summarized in chapter one. Chapter two presents the methods of the literature review and the appraisal of the literature. In the third chapter, literature is reviewed in more depth regarding family coping and adaptation and programs designed to increase coping and positive family adaptation. Chapter four concludes this paper with a guideline recommendation and a discussion of the necessary future research and recommendations related to interventions for families coping with epilepsy.

Background: What is Epilepsy?

Epilepsy is a chronic illness usually diagnosed after the occurrence of three or more seizures (Winland-Brown & Rhoads, 2007). Epilepsy occurs most often in children between the ages of three and five, or adults ages 65 and older (The National Society for Epilepsy, 2009). To understand the effect of epilepsy, the pathophysiology of the condition must be understood. Epilepsy is a disorder of the brain in which seizures frequently take place. Abnormal neuronal excitability is the major cause of seizures. The excitability of neurons is regulated by molecular
complexes inside membranes such as ion pumps or control gated ion channels (Winland-Brown & Rhoads, 2007). If a malfunction occurs within the membranes, a person may develop seizures and/or epilepsy. The areas of the brain which are most often involved with repetitive misfiring are the motor cortex, the hippocampal formation, and the amygdaloid complex (Winland-Brown & Rhoads, 2007). Genetics may also play a part in seizures and epilepsy, but the exact contribution of genetics is not currently known. Other causes of seizures or epilepsy include medications, head trauma, strokes, degenerative diseases, infections, tumors, and brain malformations. A diagnosis of epilepsy is made when a person has three or more seizures. A seizure is behaviorally characterized by an abrupt unconscious change in behavior, movement, autonomic function, or sensation. There are three types of epileptic seizures: partial seizures, generalized seizures, and unclassified seizures (Winland-Brown & Rhoads, 2007).

Partial seizures are initiated in a cerebral hemisphere of the brain and are further classified based on whether or not consciousness is lost in the individual. A simple partial seizure involves no loss of consciousness but may involve motor symptoms, sensory symptoms, and autonomic or psychic symptoms (Winland-Brown & Rhoads, 2007). Complex partial seizures may begin as a simple partial seizure and progress to a complex partial seizure. Complex partial seizures involve a loss of consciousness and may involve some behavioral automatisms (unconscious repetitive motor actions) (Winland-Brown & Rhoads, 2007). It is currently thought that simple partial seizures usually have unilateral hemispherical involvement, while complex partial seizures usually have bilateral hemispherical involvement (Winland-Brown & Rhoads, 2007). Partial seizures can also develop into generalized seizures.
Generalized seizures usually involve both hemispheres of the brain. Motor symptoms, electroencephalography changes, and neuronal discharges of a generalized seizure occur bilaterally over the brain and body (Winland-Brown & Rhoads, 2007). This type of seizure usually involves misfiring of the neurons, which occurs largely in both hemispheres (Winland-Brown & Rhoads, 2007). There are six types of generalized seizures: absence, myoclonic, clonic, tonic, tonic-clonic, and atonic seizures (Winland-Brown & Rhoads, 2007). Absence seizures occur without any real interruption of current activity, typically last less than thirty seconds and usually involve a blank stare or slowed or slurred speech. (Winland-Brown & Rhoads, 2007). Myoclonic seizures are short jerking movements that may be localized to the face, trunk, or extremities (Winland-Brown & Rhoads, 2007). Tonic seizures involve generalized stiffening, or rigidity, of the body (Winland-Brown & Rhoads, 2007). Clonic seizures are convulsive in nature. A convulsion is the continuous rapid contraction and relaxation of muscles in the body. Convulsive seizures differ in length depending on the individual (Winland-Brown & Rhoads, 2007). Tonic-clonic seizures start with rigidity of the entire body and lead into generalized convulsions (Winland-Brown & Rhoads, 2007). Atonic seizures occur when the individual becomes unsteady, or astatic (Winland-Brown & Rhoads, 2007). These attacks are also referred to as “drop attacks” because they may cause the individual to fall to the ground without warning. As a rule, myoclonic, tonic, clonic, tonic-clonic, and atonic seizures may last a few seconds to several minutes. On rare occasions, seizures may continue for hours or even days. This condition is called status epilepticus (Winland-Brown & Rhoads, 2007). Overall, epilepsy is a disabling, chronic condition that involves many different components of management.
Management of epilepsy is complicated, and often requires a complex, rigid, and expensive medication regimen in order to control seizure activity. In general, epilepsy medications focus on the maintenance of certain neurochemicals within the brain in order to decrease abnormal electrical impulses that lead to seizure activity (PubMed Health, 2009). The medications that are often used, especially more recently, for adults and children with epilepsy are carbamazepine, ethosuximide, lacosamide, rufinamide, gabapentin, lamotrigine, levetiracetam, oxcarbazepine, phenobarbital,phenytoin, pregabalin, tiagabine, topiramate, valproic acid, and zonisamide (French, Kanner, Bautista, & Abou-Khalil et al., 2004). French et al. (2004) also explained that the common complications of these anti-epileptic medications in children and adults are lethargy, dizziness, anxiety, nervousness, somnolence, and headache. Prescribing and dosing anti-epileptic drugs in children can be a particularly difficult task.

The general rule for prescribing anti-epileptic drugs in children is to prescribe enough medication to stop seizures without causing side effects. Dosing of anti-epileptic drugs is entirely dependent on each individual child. In addition to medications, epilepsy management techniques include the use of deep brain stimulators and vagus nerve stimulators. Deep brain stimulators are implanted within the brain and send impulses to the cerebellum to increase seizure control by stimulating deep brain structures, while vagus nerve stimulators are implanted near the clavicle and send an electrical impulse to stimulate the vagus nerve in the neck (Loddenkemper, Pan, Neme, & Baker et al., 2001). Another treatment option for epilepsy is surgery to remove the portion of the brain where the seizures originate (i.e., temporal lobectomy) but this technique is not often used in children (Wiebe, Blume, Girven, & Eliasziw, 2001). Another possible preventive measure for epilepsy in children is avoidance of triggers for
seizures. Many children with epilepsy have triggers for seizures such as foods, scents, or other environmental factors. If these triggers can be identified, seizures may be more easily controlled. When used in some combination, all of these treatment methods have shown effectiveness, however, there are few treatments that keep individuals entirely seizure free.

**Significance of the Problem: How many Children have Epilepsy?**

Epilepsy currently affects approximately 2.5 million Americans, of which 300,000 are children (Center for Disease Control and Prevention, 2009b). Most cases of epilepsy are diagnosed in children under the age of 14 (Epilepsy Foundation, 2009). The current literature describes coping mechanisms and intervention strategies for families coping with the negative effects of a chronic condition such as: asthma, diabetes, childhood cancers, and cardiac conditions (LeMaistre, 1999). However, family interventions for children with epilepsy have not been effectively disseminated into practice.

**Family Stress and Coping When a Child has Epilepsy**

Epilepsy is a chronic condition that can be traumatic on the child with epilepsy and his or her family. Families vary in their ability to cope with childhood epilepsy and this may affect overall family adaptation. Without the ability to adapt to having a child with epilepsy, families may not effectively manage the child’s condition. Effective management of epilepsy is extremely significant for decreased seizure activity and positive adaptation.

Relationships between family members are also significant to each individual family member’s overall adaptation and stress level. Hanson & Kaakinen (2001) explain that individuals cannot be entirely understood without information regarding their families, and they also emphasize the interconnectedness of all individuals, especially those that share a family
unit. They state “The family is viewed as a whole, not as merely the sum of its parts” (Hanson & Kaakinen, 2001, p. 44). Normal family relationships are extremely important for the adaptation of a family unit because family members have a special interrelatedness, especially in the face of illness and other health-related beliefs and experiences. The family stress and coping theory (FSCT) provides a strong framework for discussion of family coping and adaptation to having a child with epilepsy. (Zeitlin, 1986).

The basic assumption of FSCT is that the experience of stress is normal. However, families must employ effective coping mechanisms in order to maintain their equilibrium during stress. Their ability to cope depends on a number of factors, including the availability of necessary resources, including knowledge, skills, and emotional support. The outcome will be overall positive adaptation or negative adaptation (Plunkett, 2003).

Major concepts relevant to management of epilepsy-related issues are: stressors, resources, appraisal, coping strategies, and family adaptation (Plunkett, 2003). Stressors are events that occur within a family that have the ability to affect or alter the functioning of the family (Plunkett, 2003). Resources are “the properties, attributes, or skills that individuals or families have at their disposal when adapting to stressor events” (Plunkett, 2003, p. 1). Appraisal is the process of determining the value of the stressor or stressors. Coping strategies are the methods a family uses to help get through stressful situations. These strategies can be used by the entire family or by individuals within the family. Family adaptation is the result of a family’s attempt to adjust and change after a stressor or stressors have occurred within the family (Plunkett, 2003). Where epilepsy is concerned, having a child with epilepsy is the stressor. A crisis occurs in the family when there are not enough resources to support family coping and
positive adaptation. Of particular interest in this discussion are interventions, based on the FSCT model, which are designed to provide families with resources such as knowledge about epilepsy and social support, in order to strengthen the family’s coping and positive adaptation.

**Significance to Healthcare Providers**

The role of the advanced practice nurse in pediatric epilepsy is to care for the child and his or her family. Advanced practice nurses are often responsible for diagnosing epilepsy and managing care of children with epilepsy and their families (Schachter, 2004). The nurse practitioner may strengthen family coping and adaptation by providing resources necessary to increase positive adaptation and family health. Advanced practice nurses must have knowledge of interventions for families coping with epilepsy in order to provide resources for stress management, positive adaptation, and effective coping mechanisms. This knowledge will allow for better treatment and care of children with epilepsy and their families. Because family may be an important constant in the child’s life, it is extremely important for the advanced-practice nurse to provide family-centered care to children and families coping with epilepsy.

The issue of family coping and adaptation related to epilepsy is also significant to nursing because nurses must have the knowledge to effectively care for children with epilepsy and their families in all healthcare settings (Schachter, 2004). Nurses are often responsible for the care of children with epilepsy within hospitals, healthcare clinics, and when home health is necessary. Nurses have a responsibility to educate individuals with epilepsy and their families, and are also involved in the assessment of whether or not management and treatment interventions are successful (Schachter, 2004).
The management of the physical and psychological effects of epilepsy is truly important to all healthcare providers in any healthcare setting because seizures may occur at any time without warning. Healthcare providers need to be aware of the types of seizures and their effects in order to safely and effectively care for individuals with epilepsy. All healthcare providers also have a responsibility to include families in the care of children with epilepsy (Morrell, 2002). Healthcare providers should be able to educate children and their families about what to expect with a diagnosis of epilepsy, and where they can get the resources they need for positive coping and adaptation (Morrell, 2002).

**Summary and Conclusion**

Currently, approximately 2.5 million Americans have been diagnosed with epilepsy (Center for Disease Control and Prevention, 2009b). It is important for nurses to have an understanding of the possible negative effects of epilepsy such as decreased familial coping and adaptation abilities, and increased family stress levels. Nurses have a responsibility to apply current findings and knowledge regarding family interventions for epilepsy to both the child with epilepsy and his or her family. The Family Stress and Coping Theory is an appropriate framework for this paper because it encourages families to identify coping needs and areas of stress and poor adaptation, which in turn, may help advanced practitioners to provide more effective care for children with epilepsy and their families. A best practice guideline for advanced practice nurses which is framed within the FSCT may greatly improve coping, adaptation, and family outcomes for families affected by epilepsy.
CHAPTER II: METHODS

Introduction

In chapter one, the background of epilepsy was discussed. Chapter two will discuss the methods used to search, review, and appraise the research that is presented in chapter three. The literature review, synthesis, and results of the literature review will be presented in chapter three, and a guideline recommendation will be established in chapter four.

Literature Review Methods

The review of literature was based on the methods described by Burns and Grove (2009) in “The practice of nursing research: Appraisal, synthesis, and generation of evidence.” The purpose of the literature review was to examine the effect of epilepsy on the stress, coping, and adaptation of children and families affected by epilepsy, and to determine which previous interventions have been successful for children and families coping with epilepsy and other chronic conditions. Burns and Grove (2009) described three main principles of reviewing relevant literature. Those principles include searching the literature, reading and critiquing the literature, and writing the review of literature.

Searching the Literature

Burns and Grove (2009) explained that the literature search must be carried out systematically and should include the development of a search strategy. They also suggest enlisting an experienced librarian to help in the search of relevant literature. The literature search strategy should include selecting databases and keywords, recording references, and locating relevant literature. Burns and Grove (2009) suggested the use of a bibliographical database where indexes, abstracts, full text, and citation searches can be accessed. They also
specifically suggested the use of the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and MEDLINE databases when searching for medical journals. Keyword selection should be based on the most pertinent and appropriate concepts related to the ideas of the study. These concepts should reflect the study population, intervention, and/or relevant outcomes (Burns & Grove, 2009). Recording references involves the listing of the reference in the paper and reference list. According to Burns and Grove (2009), many journals and academic institutions are currently using the American Psychological Association’s (APA) format for writing research papers. When literature search results are returned, the literature should then be examined to determine which results are relevant to the keywords and topic of the study. Results may be limited if necessary, or if the search results yield an unmanageable number of articles/papers. Locating relevant literature can be conducted by first reading the abstract for relevance and saving potential literature for a more in depth examination of relevance (Burns & Grove, 2009).

For this paper, comprehensive and rigorous literature searches were performed to identify studies related to coping with epilepsy and interventions for families coping with epilepsy. Two electronic searches of all University of Arizona Health Sciences Library (AHSL) databases were conducted with the help of an experienced AHSL librarian. The first search used keywords epilepsy, family, and coping, and the second search used keywords epilepsy, family, and interventions. These searches generated 154 results. There were no limitations placed on language of the article, date of publication, co-morbidities, sex, race, or age. After all abstracts were reviewed from these searches, a total of 24 articles from the literature searches were considered relevant to the paper topic. All 24 articles were then examined in depth to ensure
relevance to this paper. A second literature search of all AHSL databases related to interventions
for families coping with chronic conditions, other than epilepsy, was also performed due to a
lack of previous and current information related to family interventions for families coping with
epilepsy. This search utilized keywords chronic conditions and interventions. This literature
search generated 53 results. There were no limitations placed on language of the article, date of
publication, co-morbidities, sex, race, or age. After all abstracts were reviewed from this search,
a total of five articles from the second literature search were considered relevant to the paper
topic. All five articles were then examined in depth to ensure relevance to this paper. In
recording each of the selected references, APA format was applied.

**Reading and Critiquing the Literature**

The purpose of reading and critiquing sources is to gain insight into the previous
knowledge about the topic being studied. Burns and Grove (2009) explained that a summary of
current knowledge is often provided in research papers. The main principles of reading and
critiquing the literature discussed by Burns and Grove (2009) are skimming sources,
comprehending sources, analyzing sources, and synthesizing sources. Skimming a source is a
brief way to gain insight into the subject matter of the source. It is commonly the process of
reading major headings, introductions, and the abstract of a paper. Skimming a source is a way
to make an initial judgment about the relevance of the source to the topic of study (Burns &
Grove, 2009). Comprehending a source requires the researcher to conduct an in depth
examination of the study to determine its quality and relevance to the study topic.
Comprehending a source often includes taking notes from the source and highlighting important
points made in the source (Burns & Grove, 2009). Analyzing sources is the idea of critiquing
each individual source, and then critiquing all sources as a whole. This allows for the determination of previous knowledge, identification of methodologies and knowledge gaps, the comparison of previous literature, and the formulation of a research problem (Burns & Grove, 2009). The synthesis of the literature is a way of bringing the literature all together to compare and contrast ideas from different authors. The synthesis of literature also determines what information is known about the problem topic, and what may have been done to alleviate the problem in the past (Burns & Grove, 2009).

For this paper, each source was initially skimmed per the recommendations of Burns and Grove (2009). Through the skimming process, articles were deemed relevant or irrelevant. The articles that were deemed relevant were then moved on to the comprehending process. During this process, each article was read in depth, notes were taken, and areas of importance were highlighted for future reference. Each article was summarized for the purpose of this paper. Each source was then analyzed by critiquing each individual source, and then critiquing all sources as a whole. Through this analysis, previous knowledge about the effects of epilepsy on families was identified, and different interventions for families of children with epilepsy were identified and examined. This analysis helped in the identification of the problem discussed in this paper. The quality of the previous intervention literature was analyzed. This quality analysis will be discussed later in this chapter. After analysis, a synthesis of the literature was performed. Through this synthesis, all of the ideas of the literature were compared and contrasted, and ideas regarding future interventions were generated.
Writing the Literature Review

Burns and Grove (2009) explain that a literature review is meant to act as evidence that a problem or knowledge gap exists in the study area. They explain that there is no required or recommended length of a literature review, but that it should review the important concepts of the paper and describe how they relate in order to act as the prior knowledge about the topic. Burn and Grove (2009) identified three important areas of writing the review of literature. These areas are sorting your sources, developing a written review, and checking references. According to Burn and Grove (2009), sources should be sorted in an organized manner that reflects the current knowledge about the topic and the knowledge gap related to the topic. The sources should also be organized in a way that provides the reader with the background information necessary to understand the importance of the problem statement (Burns & Grove, 2009). The purpose of developing a written literature review is to present the background information that is pertinent to the topic of the paper (Burns & Grove, 2009). Burns and Grove (2009) have identified the major sections of the literature review as the introduction, the discussion of literature, and a summary. They also explained that the presentation of the literature may be completed in a narrative manner or in a table, and should provide significant information related to the paper topic and the knowledge gaps that have been identified through the literature review. The review of literature should also present the conclusions that have been drawn from the literature reviewed (Burns & Grove, 2009). All of the sources in the literature review should be listed in the reference list and should be accurately recorded (Burns & Grove, 2009). Burns and Grove (2009) recommend checking all in-text citations against the reference list to ensure they have all been included in the list.
The sources in this paper have been systematically organized in the literature summary and review. **The literature summary initially examines the effect of epilepsy on families of children with epilepsy.** The summary then examines the effect of different interventions on the coping and adaptation of families of children with epilepsy and chronic conditions. These topics provide background information related to the problem presented in the paper. The presentation of literature is presented in a narrative manner in this paper, and all of the sources in the literature review are strongly related to the topic of the paper. The knowledge gaps were identified from the literature review and conclusions were drawn based on the information gathered from the literature review. All of the sources in the literature summary and review have been included in the reference list, and all in-text citations have been checked against the reference list to ensure they have been included in the reference list of this paper.

**Methods used to Appraise the Existing Literature**

The research appraisal for this paper was based on Newhouse et al.’s (2007) “Johns Hopkins nursing evidence-based practice model and guidelines.” The purpose of these guidelines is to allow for the appraisal of the strength and quality of the evidence reviewed in an evidence-based paper. Newhouse et al. (2007) explain how to rate evidence using two different schemes. The first scheme is a way of rating the strength of the research evidence, and is rated on a scale of I to V. The second scheme is a way of rating the quality of the evidence, and is rated A through C (Newhouse et al., 2007). The two different ratings are then combined to determine the overall value of the research.
**Rating the Strength of the Evidence**

Per Newhouse et al. (2007), the strength of the evidence should be rated on a I to V scale. Level I is considered the strongest type of evidence, and it consists of experimental studies, randomized controlled trials, or meta-analyses of randomized controlled trials. Level II consists of quasi-experimental studies. Level III consists of non-experimental studies, qualitative studies, and meta-syntheses. Level IV is based on the opinions of well-known experts and includes systematic reviews and clinical practice guidelines. Level V is the opinion of one expert on non-research evidence including case studies, literature reviews, organizational or personal experiences, and clinical expertise. Level V is considered the weakest type of evidence (Newhouse et al., 2007).

**Rating the Quality of the Evidence**

Per Newhouse et al. (2007), the quality of the evidence should be rated A through C. Level A is considered the highest quality evidence and includes an adequate sample size and control, consistent results, recommendations consistent with the literature review, reference to scientific evidence, well-defined and reproducible search strategies, consistent results, and definitive conclusions, rigor, well-defined methods, and reliable and valid measures. Level B is considered good quality evidence. Level B includes, reasonably consistent results, adequate sample, some control, fairly definitive conclusions, recommendations consistent with a comprehensive literature review, scientific evidence, thorough search and search approach, evaluation of strengths and limitations, well-defined methods, and reliable and valid measures. Level C is considered the lowest quality evidence. Level C includes little evidence with inconsistent results and poorly defined search strategies, insufficient sample size, insufficient
evidence to make conclusions or recommendations, poorly defined methods, poor reliability and validity of measures, and non-discernable expertise of the researcher.

**Table of the Appraisal of the Intervention Research**

The intervention research presented in this paper was appraised according to Newhouse et al. (2007). Table 1 below shows the quality and strength information and ratings for each of the 14 intervention articles related to epilepsy and chronic illness.

**Table 1. Strength and Quality Ratings for the Intervention Articles Reviewed**

<table>
<thead>
<tr>
<th>Article Author, Date and Program Type</th>
<th>Research Type</th>
<th>Strength and Quality Information</th>
<th>Strength Rating</th>
<th>Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>May and Pfafflin (2002) Psychoeducational Program</td>
<td>Literature Review</td>
<td>This research paper is a literature review and is based on individual opinion. They reviewed a large number of articles and had definitive conclusions. The recommendations were consistent with the literature review and strengths and limitations were identified.</td>
<td>V</td>
<td>B</td>
</tr>
<tr>
<td>Snead, Ackerson, Bailey, and Schmitt et al. (2004) Psychoeducational Program</td>
<td>Quasi-Experimental Design</td>
<td>This paper had a sufficient sample, definitive conclusions based on the outcomes, a comprehensive literature review, well-defined methods, and consistent recommendations.</td>
<td>II</td>
<td>B</td>
</tr>
<tr>
<td>Study Title</td>
<td>Design Type</td>
<td>Quality</td>
<td>Rating</td>
<td></td>
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<td></td>
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<tr>
<td>Fernandes and Souza (2001) Support Group</td>
<td>Quasi-Experimental Design</td>
<td>This paper had a sufficient sample, definitive conclusions based on the outcomes, a comprehensive literature review, well-defined methods, and consistent recommendations.</td>
<td>II</td>
<td>B</td>
</tr>
<tr>
<td>Wohlrab, Rinnert, Bettendorf, and Fischbach et al. (2007) Famoses Group</td>
<td>Quasi-Experimental Design</td>
<td>This paper had an insufficient sample and a limited explanation of the literature search strategies, but provided definitive conclusions based on the outcomes, a comprehensive literature review, well-defined methods, and consistent recommendations.</td>
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<td>Glueckauf, Fritz, Ecklund-Johnson, and Liss et al. (2002) Videoconferencing and Speakerphone Meetings</td>
<td>Quasi-Experimental Design</td>
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<td>Loding, Wold, &amp; Skavhaug (2007) Group Meeting/Education Program</td>
<td>Quasi-Experimental Design</td>
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<td>Burke, Handley-Derry, &amp; Costello et al. (1997)</td>
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<td>Schultz, Schultz, &amp; Bruce et al. (1993)</td>
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Conclusion

The methods of this paper were based on Burns and Grove (2009) and Newhouse et al.’s (2007) guidelines for reviewing and appraising literature. The review and appraisal of the literature were helpful in formulating and recommending a guideline for children and families coping with epilepsy. Based on the literature review and appraisal of the literature, a guideline recommendation may be made to help provide an inclusive and well-rounded intervention for families who are affected by epilepsy. The results section of this paper presented in chapter three shows the extreme effect of epilepsy on children and their families, and also identifies the significant interventions that have improved the coping and adaptation of families affected by epilepsy or another chronic condition. The results of the literature review helped to determine the best and most effective interventions that have been previously used for families coping with epilepsy. The intervention guideline recommendation for this paper is based on the results of the literature review in this paper. Chapter four will discuss the guideline recommendation, implications, limitations, and necessary future research related to this topic.
CHAPTER III: LITERATURE REVIEW, SYNTHESIS, AND RESULTS

Literature Review

Comprehensive and rigorous literature searches were performed to identify studies related to coping with epilepsy and interventions for families coping with epilepsy. Electronic searches of all University of Arizona Health Sciences Library databases were conducted. These searches generated 154 results. There were no limitations placed on language of the article, date of publication, co-morbidities, sex, race, or age. A total of 24 articles from the literature searches were relevant for this review. A later search related to interventions for families coping with chronic conditions, other than epilepsy, was also performed due to a lack of previous and current information related to family interventions for families coping with epilepsy. The purpose of this second literature search was to determine the interventions that have been used for families coping with other chronic illnesses that may cause comparable stresses to epilepsy. This literature search generated 53 results. There were no limitations placed on language of the article, date of publication, co-morbidities, sex, race, or age. A total of five articles from the second literature search were found to be relevant to this paper.

This chapter provides a review of research about adaptation of families of children with epilepsy, and about interventions to strengthen family coping and adaptation for families coping with epilepsy and other chronic conditions. The chapter closes with a summary and conclusion, calling for implementation of programs to provide necessary resources for families that include a child with epilepsy.
Family Coping and Adaptation

This section reviews 15 articles about families with children who have epilepsy, including research reports and meta-analyses. The articles include research about family stress and decreased coping that can decrease family adaptation.

When a Child has Epilepsy

Stanton (1999) conducted a review of research about family coping and adaptation when a child in the family had a neurological condition including epilepsy. The purpose of the review was to determine the psychological effect of epilepsy on children with epilepsy and their families. The author suggested that children with epilepsy have lower self-esteem, higher rates of depression, and increased behavior troubles in comparison to children not suffering from a neurologic condition (Stanton, 1999). The author also suggested that families of children with epilepsy play a large role in the adaptation of children with epilepsy (Stanton, 1999). According to this review, many cross-sectional studies have been conducted in order to investigate family adaptation and coping, and its relationship to the adaptation and coping in children with epilepsy (Stanton, 1999). The author discussed the idea that there are relationships between weak family coping, depression, and behavioral troubles (Stanton, 1999). The author also suggested that a lack of proper intervention and educational resources could cause these problems (Stanton, 1999). Maternal attitudes were also discussed in this review. The author explained that maternal attitudes about epilepsy could cause inadequate adaptation for the child with epilepsy and other family members (Stanton, 1999). The researcher looked at the possibility that family members of children with epilepsy think of that family member as ill or different. The author suggested that this could also cause poor adaptation for the child with epilepsy (Stanton, 1999). The author
concluded that more research should be done to gain further information about the relationship between family coping, adaptation, and epilepsy, and the author stressed the importance of this research in determining families at greater risk for adaptation and coping problems (Stanton, 1999).

A study by Wood, Sherman, Hamiwka, and Blackman et al’s (2008) described how epilepsy can affect the siblings of children with epilepsy. The authors, which included an advanced practice nurse, surveyed thirty seven siblings of children with epilepsy about their anxiety, depression, and quality of life, using self-report measures: the Manifest Anxiety Scale, Children’s Depression Inventory, and Peds Quality of Life questionnaire (Wood et al., 2008). Parents were also surveyed to assess child behavior through the Child Behavior Checklist (Wood et al., 2008). The research showed that only two of the children had anxiety about their siblings’ epilepsy (Wood et al., 2008). No child scored in the clinical depression range on the Children’s Depression Inventory (Wood et al., 2008). However, there was a pattern of lower scores, as compared to the normative mean, on the Peds Quality of Life questionnaire for siblings of children with epilepsy (Wood et al., 2008). Using the Child Behavior Checklist, 25 percent of parents reported that their non-epileptic child had increased internalizing behaviors, which are behaviors where a child keeps to him/herself and does not openly share thoughts, feelings, or concerns (Wood, et al., 2008). The study concluded that siblings of children with epilepsy have good adaptation and coping overall (Wood et al., 2008). However, this study did not take into account any other possible variables for the decreased quality of life and possible internalizing behaviors such as parental coping or other family stressors. However, the authors did discuss the
idea that more research must be done to determine the significance of this research (Wood et al., 2008).

Chapieski, Brewer, Evankovich, and Culhane-Shelburne et al. (2005) discussed the effect of maternal anxiety on children with epilepsy and their families. The purpose of the study was to assess how epilepsy affects the mother of a child with epilepsy, and how the mother of a child with epilepsy affects the rest of the family. The authors specifically looked at “parental overprotection” and “child adaptive functioning” (Chapieski, Brewer, Evankovich, Culhane-Shelburne, et al., 2005, p. 246). The researchers studied 56 mothers who had children with epilepsy (Chapieski et al., 2005). The researchers also looked at family and maternal attributes in order to compare families to one another. The authors used a survey to determine the mothers’ anxiety regarding epilepsy, and the level of adaptation of children with epilepsy whose mothers have increased anxiety levels (Chapieski et al., 2005). The results of the study showed that mothers of children with epilepsy had increased levels of anxiety (Chapieski et al., 2005). The survey also showed that the main predictors of maternal anxiety were decreased coping resources and increased family stress (Chapieski et al., 2005). The survey also found that maternal anxiety was closely related to overprotective parenting styles and excessively commanding parenting (Chapieski et al., 2005). The researchers discovered that maternal anxiety was associated with decreased adaptive functioning in the children of these families (Chapieski et al., 2005). The authors suggested that more research be conducted to better understand the relationship between maternal anxiety and decreased adaptive functioning in children with epilepsy (Chapieski et al., 2005).
Sherman, Hamiwka, Blackman, and Wirell et al. (2008) focused on the impact of epilepsy on the child’s mother and family. The study aims were to “determine the prevalence of depression and sleep disruption in mothers of children with intractable epilepsy, and assess which family factors and neurologic/behavior characteristics of a child with epilepsy correlate with maternal depression” (Sherman et al., 2008, p. 418). The researchers, which included an advanced practice nurse, studied 52 mothers of children with epilepsy ages two to 18 years of age (Sherman et al., 2008). Each mother filled out the Beck Depression Inventory and Pittsburgh Sleep Questionnaire to assess maternal depression and sleep patterns (Sherman et al., 2008). Each mother also filled out the Child Behavior Checklist, Attention Deficit Hyperactivity Disorder Rating Scale, and the Scale of Independent Behavior which was modified for each child (Sherman et al., 2008). The researchers also reviewed each child’s chart to determine seizure onset, activity, frequency, type, and treatments (Sherman et al., 2008). The mothers were also surveyed about their family characteristics, income, education, and number of children (Sherman et al., 2008). Of the 52 mothers who returned their questionnaires and surveys, 25 percent were moderately to severely depressed, and 67 percent had sleep disturbances (Sherman et al., 2008). The mothers who reported depression and sleep disturbances also reported higher levels of attention deficits and behavioral issues in their children. This research showed that maternal depression was associated with attention deficits and behavioral issues in children (Sherman et al., 2008).

Oostrom, Schouten, Kruitwagen, and Jennekens-Schinkel et al. (2001) looked at parent perceptions and responses to epilepsy. The purpose of the study was to assess how epilepsy affects the parents of children with epilepsy. The researchers used a content analysis to collect
data about parent perceptions and epilepsy. The researchers interviewed parents of 69 children with epilepsy, and then the content analysis was performed (Oostrom et al., 2001). Each parent was questioned about chronic behavior problems in their child, chronic learning problems in their child, family problems, new parenting styles due to epilepsy, and child responses to changes caused by epilepsy (Oostrom et al., 2001). Based on the content analysis, 33 percent of parents perceived themselves as being “thrown off balance” because they had a child with epilepsy (Oostrom et al., 2001, p. 1452). About 48 percent of parents said they were not comfortable with parenting after the onset of seizures in their children (Oostrom et al., 2001). Parents felt that about 24 percent of their children had been “thrown off balance” by the diagnosis of epilepsy (Oostrom et al., 2001, p. 1452). The parents also felt that 35 percent of their children had chronic behavior troubles, and 15 percent had chronic learning difficulties (Oostrom et al., 2001). About 33 percent of parents reported family problems due to having a child with epilepsy (Oostrom et al., 2001). Overall, the researchers suggest more research in this area (Oostrom et al., 2001).

Baki, Erdogan, Kantarci, and Akisik et al. (2004) discussed the idea that children with epilepsy have higher rates of depression and anxiety as compared to children without epilepsy (Baki et al., 2004). However, the main purpose of this research was to show the impact on the family members of children with epilepsy, specifically in the mothers of children with epilepsy. This study was executed using a cross-sectional design that looked at 35 children and adolescents with epilepsy, as well as 35 comparable controls (Baki et al., 2004). The Kovac Child Depression Inventory and State-Trait Anxiety Inventory for Children were administered to the children, and the Beck Depression Inventory and State-Trait Anxiety Inventory were
administered to the mothers (Baki et al., 2004). The scores showed that children with epilepsy were more depressed than children without epilepsy (Baki et al., 2004). However, the scores were not significantly different between the experimental and control groups for the State-Trait Anxiety Inventory for Children (Baki et al., 2004). The maternal scores for both the Beck Depression Inventory and the State Trait Anxiety Inventory were not different from the controls to the experimental group (Baki et al., 2004). The researchers suggested that children with epilepsy may have increased levels of depression, but that mothers are not severely affected by the diagnosis of epilepsy. The authors also stated that further research is necessary to determine how mothers of children with epilepsy are affected by epilepsy (Baki et al., 2004).

Mims, an advanced practice nurse, (1997) looked at the psychosocial effect of epilepsy on siblings of children with epilepsy. The purpose of the study was to assess the effects of epilepsy on siblings of children with epilepsy. The researcher explained that past studies have focused mostly on the child with epilepsy, but have paid little attention to the family members of the child with epilepsy. The study was a comparative study that had two experimental groups and a control group. The experimental groups consisted of 20 children whose siblings either had frequent seizures or infrequent seizures (Mims, 1997). Each group was assessed in the areas of self-esteem, behavioral and social functioning, and family stress using the Piers-Harris Self-Concept Scale, Child Behavior Checklist, and Family Inventory of Life Events (Mims, 1997). The siblings of children with epilepsy also completed the Sibling Concern about Seizure Scale in order to provide information about their feelings about epilepsy (Mims, 1997). This research showed no real difference between self-esteem and social functioning among any of the three groups (Mims, 1997). The study did show that siblings of epilepsy patients have an increased
level of externalizing behaviors, which often come in the form of aggression, hyperactivity, and disruptive behavior (Mims, 1997). The siblings of patients with frequent seizures showed more evidence of externalizing behaviors and increased concerns about epilepsy than the siblings of patients with infrequent seizures (Mims, 1997). The study also showed that there is significantly more stress among families dealing with a child who has frequent seizures versus a family dealing with a child who has infrequent seizures or no chronic illness at all (Mims, 1997). The study concludes by emphasizing the idea that family adaptation and coping should be taken into account when planning care for an epilepsy patient and his or her family (Mims, 1997).

Camfield, Breau, and Camfield (2001) focused on creating a new tool for parents coping with epilepsy. The purpose of the study and study tool was to assess the impact on family life when coping with a child who has epilepsy. The researchers developed an 11-item scale to “evaluate the influence of epilepsy on the major aspects of their family and child’s life” (Camfield, Breau, & Camfield, 2001, p. 104). The idea was that the scale would be helpful for clinicians to use when caring for families coping with epilepsy, and for other research studies (Camfield, Breau, & Camfield, 2001). The scale created was the Impact of Pediatric Epilepsy Scale (Camfield, Breau, & Camfield, 2001). The researchers recruited 97 mothers of children ages two to 16 years old, and had them fill out a visual analogue scale to assess the child’s quality of life, and the Impact of Pediatric Epilepsy Scale to assess “academic achievement, participation in activities, health, relationships with family and with peers and siblings, social activities, self-esteem, and the caregiver’s hope for his or her child’s future” (Camfield, Breau, & Camfield, 2001, p. 104). In order to test the validity of the scale, it was compared with other similar questionnaires. The questionnaire was shown to have validity in comparison to other
similar questionnaires (Camfield, Breau, & Camfield, 2001). The new scale did show that parents of epilepsy patients are more stressed than parents of children without any chronic conditions (Camfield, Breau, & Camfield, 2001). The scale also showed that siblings had lower self-esteem and more emotional problems than siblings of children without chronic conditions (Camfield, Breau, & Camfield, 2001). The study suggests that research tools such as the Impact of Pediatric Epilepsy Scale can help investigate the quality of life of both children with epilepsy and their families (Camfield, Breau, Camfield, 2001).

Tzoufi, Mantas, Pappa, and Kateri (2004) discussed the idea that the coping status of patients with neurological diseases has been addressed significantly (Tzoufi, Mantas, Pappa, & Kateri et al., 2004). However, the researchers suggest that family members have been overlooked (Tzoufi et al., 2004). The purpose of the study was to investigate family functioning and traits of families that include a child with a chronic neurological disease, including epilepsy (Tzoufi et al., 2004). The researchers recruited 52 parents of children with chronic neurological diseases to fill out scales and questionnaires (Tzoufi et al., 2004). These included the Family Environment Scale, the Family Burden Scale, the General Health Questionnaire, and a questionnaire about disease knowledge, coping strategies, and satisfaction with services and care provided to them (Tzoufi et al., 2004). The results of these scales and questionnaires showed that parents of children with chronic neurological diseases “discuss their problems less freely, talk less openly around home, score high on the Family Environment Scale’s subscale of conflict, and pay more attention to ethical and religious issues and values” (Tzoufi et al., 2004, p. 110). However, the study also showed that families of children with epilepsy tended to be more involved in recreational activities, were more knowledgeable about medical support of epilepsy,
and were more satisfied with medical care they received than families of patients with other chronic neurological conditions (Tzoufi et al., 2004). This research was important because it could be helpful in the future for planning and executing of coping and adaptation interventions and support services for patients with chronic neurological diseases. The researchers of this study suggested further research in this area.

Chiou and Hsieh (2007) studied the self-concept of children with epilepsy and asthma, and the parenting stress of parents of children with these conditions. The purpose of the study was to assess self-concept in children with epilepsy, and parenting stress in parents of children with epilepsy. The study was a comparative study that used 48 children with epilepsy ages eight to 13 years, and 54 children with asthma that were of comparable ages to the epileptic children (Chiou & Hsieh, 2007). The parents of these children also took part in the study. The advanced practice nurse researchers used the Harter’s Self-Perception Profile for Children in order to assess the self-concept of each child participating in the study (Chiou & Hsieh, 2007). Parents’ stress levels were measured with the Abidin’s Parenting Stress Index/Long Form (Chiou & Hsieh, 2007). Demographic information and illness severity information was collected for each child so that other potential risk factors for decreased self-concept and stress could be identified (Chiou & Hsieh, 2007). The results showed that children with epilepsy had significantly lower self-concept scores than the asthma patients (Chiou & Hsieh, 2007). The study also showed that parents’ stress levels were positively associated with lower self concept scores in the children (Chiou & Hsieh, 2007). Results suggest that parents of children with epilepsy could benefit from coping strategies that may help lower parenting stress levels, which would then positively
influence the self-esteem of their children (Chiou & Hsieh, 2007). The researchers emphasized the importance of parental coping and adaptation.

Mu, an advanced practice nurse, (2004) looked at the stresses that fathers experience when raising a child that has epilepsy. The purpose of this study was to examine the effects of epilepsy on fathers of children with epilepsy. The study explains that epilepsy can “threaten the integrity of family systems” and that some families of certain cultures can feel ashamed of a diagnosis of epilepsy in a family member (Mu, 2004, p. 367). The researchers also discuss the idea that epilepsy causes a great deal of stress, and that many families may not have proper coping strategies (Mu, 2004). This study was focused specifically on fathers of children with epilepsy because the researchers felt that this area of epilepsy and families had not been extensively researched (Mu, 2004). The researchers examined the relationship between fathering a child with epilepsy and paternal uncertainty, coping strategies, and depression (Mu, 2004). The researchers recruited 210 fathers of children with epilepsy to take the Coping Health Inventory for parents (Mu, 2004). The results showed that an increased level of paternal uncertainty was associated with a decreased level of paternal coping (Mu, 2004). Uncertainty and decreased coping were also associated with an increased level of depression in fathers of children with epilepsy (Mu, 2004). This study was unique in that it focused on the paternal experience of having a child with epilepsy. The researchers also suggested the implementation of nursing interventions to help fathers, patients, and families to better cope with having a child with epilepsy (Mu, 2004).

Aguiar, Guerreiro, McBrien, & Montenegro (2007) focused their research study on the quality of life of children with epilepsy, and the impact of epilepsy on school attendance in these
children. The purpose of the study was “to evaluate the impact of ongoing seizures on school attendance amongst children with epilepsy” (Aguiar et al., 2007, p. 698). The researchers used a prospective study design at the University of Campinas Pediatric Epilepsy Clinic (Aguiar et al., 2007). The study included 50 children ages six to 18 years old that had been diagnosed with epilepsy (Aguiar et al., 2007). Parents of these children were interviewed using a semi-structured questionnaire focused on their child’s academic activity related to the diagnosis of epilepsy (Aguiar et al., 2007). The authors discussed the idea that academic activity, including school attendance, is impacted by epilepsy. The results of this studied showed that 88 percent of the children in this study had missed at least one day of school due to seizures (Aguiar et al., 2007). The study also showed that 79.5 percent of the children in this study had missed at least one day of school due to medical appointments related to epilepsy, and 68.2 percent had missed at least one day of school due to medical tests associated with having epilepsy (Aguiar et al., 2007). The study also showed that siblings of the children in this study were academically affected by the diagnosis. The results showed that 12.5 percent of siblings of children in this study had missed at least one day of school related to epilepsy (Aguiar et al., 2007). The authors concluded that epilepsy has a significant effect on school attendance for children with this diagnosis, which may increase the risk of academic difficulties in these children (Aguiar et al., 2007).

Thornton, Hamiwka, Sherman, Tse, Blackman, & Wirrell (2007) used a cross-sectional cohort study design to study the impact of epilepsy on competence and problem behaviors in families of children with epilepsy. The researchers recruited 82 children with epilepsy from the pediatric neurology clinic at Alberta Children’s hospital (Thornton et al., 2007). Parents of these
children were asked to complete the Family Assessment Measure III and the Child Behavior Checklist for the children with epilepsy and their siblings (Thornton et al., 2007). The researchers executing this study focused on the effect of epilepsy on family functioning and adaptation related to having a family member with epilepsy. The results showed that families that included a child with epilepsy scored significantly worse on the Role Performance subscale of the Family Assessment Measure III than families who did not include a member with epilepsy (Thornton et al., 2007). This means that families that included a member with epilepsy had poor performance in the areas of the “allocation or assignment of specified activities to each family member, the agreement or willingness of family members to assume assigned roles, and the actual enactment or carrying out of prescribed behaviors” (Thornton et al., 2007, p. 91). The results also showed some correlations between competence and behavior between the children with epilepsy and their siblings (Thornton et al., 2007). The researchers explained that if increased behavior and competence problems were present in the child with epilepsy, their siblings tended to have increased behavior and competence problems as well (Thornton et al., 2007). The researchers concluded that more research is necessary in this area (Thornton et al., 2007).

Freilinger, Neussl, Hansbauer, Reiter, Seidi, & Schubert (2006) studied the psychosocial adjustment, relationships, and self-concept of siblings of children with epilepsy. The researchers used a comparative study design using study subjects and control subjects. The study utilized 68 siblings of children with epilepsy, 62 mothers of children with epilepsy, 43 fathers of children with epilepsy, and comparable control subjects for each of the three groups (Freilinger et al., 2006). The researchers administered the Child Behavior Checklist, the Self-Description
Questionnaire I and II, and the Sibling Relationship Questionnaire to the parents and siblings of children with epilepsy, as well as the comparable control groups (Freilinger et al., 2006). The results of the study showed that the mothers of children with epilepsy noticed more somatic problems in the siblings than the controls (Freilinger et al., 2006). The results also showed more nurturance of the sibling of a child with epilepsy as well as more dominant behavior in the siblings of children with epilepsy when compared to the control group (Freilinger et al., 2006). The researchers reported that siblings of children that had recently been diagnosed with epilepsy had more social problems, academic problems, and somatic complaints than the control group and siblings of children who had been diagnosed with epilepsy for a long time (Freilinger et al., 2006). The researchers concluded that families need to be closely incorporated into the care of the child with epilepsy, and should be given resource information as part of their care (Freilinger et al., 2006).

Hodes, Garralda, Rose, & Schwartz (1999) studied the expressed emotions of mothers of children with epilepsy, and the adjustment of children coping with epilepsy. The authors explained that epilepsy can change the dynamic and relationships within a family unit (Hodes et al., 1999). The authors also discussed the lack of information in this area and the need for further research in this area (Hodes et al., 1999). The study included 22 school-aged children with epilepsy from a general hospital outpatient clinic and their mothers (Hodes et al., 1999). Each of the mothers’ expressed emotions was assessed using the Camberwell Family Interview (Hodes et al., 1999). The children, their mothers, and their teachers also completed questionnaires regarding behavior, mood, and self-esteem (Hodes et al., 1999). The results of the study showed that the mothers of children with epilepsy had increased emotional
involvement in their families, and increased hostility toward their children with epilepsy versus their other children without a diagnosis of epilepsy (Hodes et al., 1999). The results also showed that mothers who were more critical of their children or had hostility toward their children had children with increased behavioral problems, antisocial behaviors, lower self-esteem, and emotional problems (Hodes et al., 1999). The authors suggest more research in this area, specifically in the area of psychological interventions for families coping with epilepsy (Hodes et al., 1999).

In summary, the major stressors identified throughout the literature review were a lack of knowledge about epilepsy, knowledge deficits about treatments for epilepsy, increased seizure frequency due to knowledge deficits about medication regimes, and emotional disturbances within the family. Throughout this literature review, the commonly identified effects of the stressors of epilepsy were increased depression within the family, increased anxiety within the family, increased behavioral problems for children in the family, decreased quality of life among members of the family, and increased stress among members of the family. In this literature review, the other themes resulting from stressors that were frequently identified for families coping with epilepsy were compromised family adaptation, decreased social participation, increased emotional problems, and increased feelings of uncertainty.

**Interventions for a Child and Family Coping with Epilepsy**

This section reviews nine articles about families of children who have epilepsy. The articles include research about family interventions for children coping with epilepsy and their families.
May and Pfafflin (2005) discussed the idea that individuals with epilepsy and their families often have knowledge deficits regarding the disease and how to effectively cope with the disease (May & Pfafflin, 2005). The purpose of this study was to determine the effectiveness of psychoeducational programs on families of children with epilepsy. The authors explained that many individuals with epilepsy have adaptation problems associated with their epilepsy (May & Pfafflin, 2005). These problems also affect the families of these individuals. The researchers also explain that there are many different types of educational programs and support programs; however, it is unclear whether or not these programs provide strategies and guide families about interventions that might be useful for adaptation and coping (May & Pfafflin, 2005). In this article, the researchers discuss the idea of providing psychoeducational programs for individuals with epilepsy. These programs give families knowledge about the disease, increase adherence, and improve coping strategies and quality of life (May & Pfafflin, 2005). The researchers of this study reviewed current literature about interventions for individuals with epilepsy. The researchers focused only on peer reviewed journals with target groups that were adults or adolescence with seizures and their family members (May & Pfafflin, 2005). Other criterion for studies reviewed was that they had to be randomized controlled trials with sample sizes greater than 12 individuals (May & Pfafflin, 2005). This review of research showed that psychoeducational programs are effective in improving the coping skills of children with epilepsy and their families. The overall results of the articles reviewed for this research were that psychoeducational programs improve epilepsy knowledge, reduce seizure frequency, improve treatment and care adherence, and improve coping and adaptation for individuals with epilepsy and their families (May & Pfafflin, 2005).
Snead, Ackerson, Bailey, and Schmitt et al. (2004) conducted a study to evaluate a six-week psychoeducational program for children with epilepsy and their families. The researchers discussed the increasing awareness of epilepsy and the need to identify effective interventions for these individuals. The researchers in this study developed six-week psychoeducational group meetings for adolescents with epilepsy and their parents (Snead et al., 2004). Prior to the group meetings, the participants took the Quality of Life in Epilepsy for Adolescents Questionnaire, the Childhood Depression Inventory, and the Revised Children’s Manifest Anxiety Scale (Snead et al., 2004). The psychoeducational group meetings provided education about “medical aspects of epilepsy, healthy lifestyle behaviors, family and peer relationships, understanding self-image and self-esteem, and stress management techniques” (Snead et al., 2004). Participants in this study were also taught about coping strategies and were given the opportunity to have open discussions about their personal experiences with epilepsy (Snead et al., 2004). The study showed that adolescents with epilepsy and their parents felt psychoeducational meetings were important for patient care for epilepsy (Snead et al., 2004). The participants also reported that they had an increased knowledge of epilepsy after the intervention (Snead et al., 2004). After the intervention, outcome measurements also showed an increased quality of life in some of the adolescents with epilepsy (Snead et al., 2004).

Fernandes and Souza (2001) aimed to validate the idea that support groups can help to identify family variables that are linked to epilepsy. The researchers gave 21 parents of children with epilepsy a pre-test regarding knowledge and treatment of epilepsy (Fernandes & Souza, 2001). The main original concerns of parents were that their child would swallow his or her tongue or have future mental disease as a result of having epilepsy (Fernandes & Souza, 2001).
The pre-test also showed overprotection of children, fear, and sadness among parents of children with epilepsy (Fernandes & Souza, 2001). To help the parents cope and improve adaptation of the family of the child with epilepsy, the researchers developed support group meetings for the families (Fernandes & Souza, 2001). At the support group meetings, they presented educational videos about epilepsy, allowed discussions between participants, and had two post-test applications for participants to complete (Fernandes & Souza, 2001). After the two post-tests, parents’ attitudes changed about epilepsy and coping with epilepsy. On the first post-test, parents said the information provided in the group meetings had changed their beliefs and made them feel more comfortable coping with epilepsy (Fernandes & Souza, 2001). In the second post-test, parents reported having fewer doubts about epilepsy, and felt that their relationships with their children were improved by the end of the group meetings (Fernandes & Souza, 2001). Overall, the support group meetings improved parent beliefs, coping, and adaptation in regard to epilepsy.

Wohlrab, Rinnert, Bettendorf, and Fischbach et al. (2007) discussed the lack of knowledge of most epilepsy patients and their families regarding the condition, treatment options, support systems, and possible health problems caused by epilepsy (Wohlrab, Rinnert, Bettendorf, & Fischbach et al., 2007). The researchers discuss the fact that there is a huge body of information available for health care workers to use as teaching tools; however, health care workers are often time limited in seeing patients and providing them with educational materials and support services (Wohlrab, 2007). The purpose of this study was to evaluate famoses groups for children with epilepsy and their families. Famoses is a form of education for children with epilepsy and their parents (European Epilepsy Academy, 2009). “It consists of two parts, a
children's course and a parents' course and it supports families in dealing with epilepsy. It also helps (others) to better understand the condition” (European Epilepsy Academy, 2009). The researchers stressed the importance of outside educational programs and resources for patients with epilepsy and their parents. For this study, a group of neuropediatricians, psychologists, social workers, and educators developed two educational programs called famoses (Wohlrab, 2007). The purpose of these two programs was to increase child and parent knowledge about epilepsy. Other aims of this study were to “help patients of childhood age and their parents achieve a better understanding of their disease, gain more self-confidence, and reduce specific fears regarding epilepsy” (Wohlrab, 2007, p. 44). The first famoses group was comprised of children ages seven to 13, and the second famoses group was comprised of the parents or caretakers of epilepsy patients (Wohlrab, 2007). The famoses groups were carried out using “interactive small-group education” (Wohlrab, 2007, p. 44). For the children, the education was done using a fictional story to explain epilepsy and its effect on children. This fictional story consisted of children sailing from one island to the next, and learning something new about epilepsy at each island (Wohlrab, 2007). The parent and caretaker famoses group discussed the aims of the program, information about epilepsy, diagnostic tools used for epilepsy, treatment of epilepsy, future expectations of epilepsy, and how to live and cope when your child has epilepsy (Wohlrab, 2007). The results of the programs showed an increased knowledge about epilepsy from both the children and parents. Both groups also said they felt more comfortable coping with the condition than they did before the famoses groups (Wohlrab, 2007). Overall, these educational groups helped to increase knowledge and adaptation of children with epilepsy and their families.
Glueckauf, Fritz, Ecklund-Johnson, and Liss et al. (2002) looked at the effect of videoconferencing and speakerphones in the home and office on coping and adaptation of teenagers with epilepsy living in rural areas. The purpose of the study was to determine whether videoconferencing and speakerphone counseling sessions are effective for children with epilepsy and their families. The researchers recruited 22 rural teenagers and their parents for participation in this study (Glueckauf, Fritz, Ecklund-Johnson, & Liss et al., 2002). The researchers, including an advanced practice nurse, implemented a six session program for each of the teenagers and their parents using either videoconferencing counseling, speakerphone counseling within the home, or office-based counseling with either videoconferencing or a speakerphone (Glueckauf et al., 2002). Prior to the six session counseling intervention, teenagers and their parents filled out Problem Severity and Frequency Scales, Social Skills Rating Systems, modified Working Alliance Inventories, and treatment adherence questionnaires (Glueckauf et al., 2002). The six sessions of counseling provided teenagers and their parents with coping and adaptation strategies, as well as education about their condition. After the six counseling sessions, the teenagers and their parents stated that they felt a decrease in problem severity and frequency (Glueckauf et al., 2002). Both the teenagers and their parents also reported an increase in social behaviors and activities after the six counseling sessions (Glueckauf et al., 2002). Overall, the counseling sessions were successful in the area of adaptation, and the sessions decreased the teenagers and parents’ feelings about how severe the condition is and how frequently it causes complications. This research allowed patients and their families to change their mindsets about the condition.
Lewis, Hatton, Salas, and Leake et al. (1991) looked at the effect of educational and adaptation programs for children with epilepsy and their parents. The purpose of the study was to evaluate a counseling intervention model for children with epilepsy and their families. The researchers, which included an advanced practice nurse, used a randomized controlled trial that tested the efficacy of a children’s epilepsy program (Lewis, Hatton, Salas, & Leake et al., 1991). The program was focused on the child and family and used a counseling model to help parents “deal with their anger, resentment, and grief related to the loss of a normal child, increase their knowledge about caring for their child, reduce anxieties relating to having a child with a seizure disorder, and improve their decision-making skills” (Lewis et al., 1991, p. 365). The researchers recruited 185 parents for the study, each of whom was given a pre-test to determine their functioning in the preceding areas (Lewis et al., 1991). Parents also filled out the Taylor Manifest Anxiety Scale to assess their anxiety levels before the intervention (Lewis et al., 1991). The parents and children separately attended four sessions that lasted one and a half hours (Lewis et al., 1991). At the end of those sessions, parents and children met together for one more hour (Lewis et al., 1991). These sessions provided coping methods, adaptation strategies, and education about epilepsy, and also allowed group discussions (Lewis et al., 1991). The comparison group consisted of parents and children without any chronic conditions. This group only attended three two hour lectures that included question and answer sessions (Lewis et al., 1991). Parents and children were tested again five months after the original pre-test to see if the intervention had made a difference (Lewis et al., 1991). The results of this study showed that parents in both the experimental group and comparison group had an increased level of knowledge about epilepsy after the sessions (Lewis et al., 1991). The results also showed that
mothers in the experimental group tended to have a decrease in their anxiety levels after the sessions (Lewis et al., 1991).

Glueckauf, Liss, McQuillen, and Webb et al. (2002) looked at the effect of a therapeutic alliance and its relationship to increased adaptation with epilepsy. This study used therapeutic alliance as an indicator of successful therapy. Therapeutic alliance is defined as the therapist-client relationship (Glueckauf, Liss, McQuillen, & Webb et al., 2002). The purpose of the study was to determine whether therapeutic alliance is an effective intervention for children with epilepsy and their families. This study involved nineteen adolescents with epilepsy and their families (Glueckauf et al., 2002). Each family was randomly assigned to either an issue specific family counseling group or a multi-family psychoeducational group (Glueckauf et al., 2002). The researchers used three different issue specific scales to evaluate coping and adaptation improvement. The researchers also used the Working Alliance Inventory to assess the thoughts of the families about their therapeutic alliance (Glueckauf et al., 2002). Each family attended six sessions in their counseling group to gain information about epilepsy, learn about coping strategies, and improve overall adaptation (Glueckauf et al., 2002). The researchers found that there was no difference between the issue specific scales among each group. However, they did find that the issue specific family counseling group had a significantly stronger therapeutic alliance than that of the psychoeducational group (Glueckauf et al., 2002). They hypothesized that this was because the specific family counseling groups were able to meet their independent goals, rather than focusing on other participants’ goals as well (Glueckauf et al., 2002). The researchers also found that there was a positive association with therapeutic alliance and therapy outcomes for the adolescents and their families (Glueckauf et al., 2002).
Cui, Wang, and Li (2000) carried out a health education intervention for patients and families coping with epilepsy. The authors recruited 103 participants from an outpatient neurology clinic for an educational intervention that included collective teaching, individual coaching and follow-up, and diary feedback (Cui, Wang, & Li, 2000). While at the clinic, nurses would provide education to patients and their parents in regard to the diagnosis of epilepsy, epilepsy medications and how to take them, and daily life issues related to epilepsy (Cui, Wang, & Li, 2000). The researchers had the patients and parents fill out the American Epileptic Life Quality Scale before the intervention, one month after the intervention, and six months after the intervention (Cui, Wang, & Li, 2000). The results of the study showed that the intervention significantly increased the quality of life in the participants (Cui, Wang, & Li, 2000). Quality of life scores were much higher at one month after the intervention than before the intervention (Cui, Wang, & Li, 2000). The results also showed there was not a significant difference in quality of life at one month after the intervention to six months after the intervention (Cui, Wang, & Li, 2000). The researchers concluded that an educational intervention for children with epilepsy and their families may improve overall quality of life for these patients and their families (Cui, Wang, & Li, 2000).

Martinuk, Speechley, Secco, Campbell, & Donner (2007) studied the effects of an educational intervention about epilepsy for fifth graders at various elementary schools. The idea behind the study was to educate children about epilepsy so that they could better understand the condition of some of their peers (Martinuk et al., 2007). This study was conducted using a stratified cluster randomized controlled trial (Martinuk et al., 2007). The researchers recruited 783 fifth graders, and gathered information about each participant’s gender, language spoken at
home, familiarity with epilepsy, school, and epilepsy knowledge and attitudes (Martinuk et al., 2007). They were then clustered into an intervention group and comparable control group (Martinuk et al., 2007). Epilepsy knowledge and attitudes were assessed prior to and one month following the intervention using a 33-item questionnaire (Martinuk et al., 2007). The results of the study showed that the intervention group had a significant increase in knowledge, while the control group showed only a slight increase in knowledge (Martinuk et al., 2007). The results also showed that the intervention group had a significant increase in positive attitudes about epilepsy, while the control group only had a slight increase in this area (Martinuk et al., 2007). The researchers concluded that an epilepsy education program can significantly increase epilepsy knowledge and positive attitudes about epilepsy (Martinuk et al., 2007). The researchers also suggested that interventions of this kind may be beneficial for children and families coping with epilepsy because it may reduce negative attitudes and stigmas about the condition (Martinuk et al., 2007).

In summary, existing research supports interventions in the form of psychoeducational programs, support groups, famoses groups, family counseling groups, educational meetings and therapeutic alliance. Psychoeducational programs include both education about the illness and psychological interventions. The support groups consist of group meetings with families and children coping with epilepsy. The famoses group intervention includes education for children with epilepsy and their families regarding the condition, treatment options, support systems, and possible health problems caused by epilepsy. The family counseling groups included education and discussion about the effects of epilepsy on the family. Therapeutic alliance interventions were focused on keeping good relationships between children with epilepsy, families, and
healthcare providers. The idea of therapeutic alliance is that families and patients will be more comfortable, confident, and compliant with their care. While all interventions proved successful for children with epilepsy and their families, some interventions reviewed were more inclusive and tended to have an impact in more areas of adaptation and coping than other interventions.

**Interventions for a Child and Family Coping with a Chronic Condition other than Epilepsy**

This section reviews five articles about families of children who have chronic conditions other than epilepsy. The articles include research about family interventions for families of children coping with chronic conditions.

The article “Assessment of the effectiveness of pediatric psychoeducational programs on family functioning” described the significance and positive effect of two separate psychoeducational programs for children with encopresis. The researcher explained that children with chronic conditions such as encopresis (i.e., the uncontrolled passage of stool in children who have been toilet trained) and their siblings are at an increased risk for coping and adaptation problems (Roblin, 2000). The researcher discussed the success of two separate types of psychoeducational programs. One program provided education and personal assistance from a nurse educator, while the other program included an educational video and management information (Roblin, 2000). The patients and families involved in each group had positive outcomes after each of the programs. Both groups were given scales to fill out in order to assess areas of family functioning before and after the psychoeducational programs (Roblin, 2000). For the patients in the nurse educator group, the results showed that families improved in the areas of illness-specific functioning, efficacy about the condition, family cohesion, peer relationships, role identification, and overall family functioning (Roblin, 2000). The group provided with
video education and management information showed improved knowledge in the areas of routine clinic care (Roblin, 2000). The overall findings were that psychoeducational programs are effective for families coping with chronic conditions and illnesses. It is clear in this study that the nurse educator psychoeducational program was more successful than the video education. However, both programs were valuable for the children and families affected by encopresis.

Loding, Wold, & Skavhaug (2007) discussed the use of a group intervention for adolescents with type one diabetes and their parents. The purpose of the study was to provide an intervention that would increase the quality of life of adolescents with diabetes and their parents. The study included 19 adolescents and their parents (Loding, Wold, & Skavhaug, 2007). The adolescents and their parents were separated into groups that met once a month for one year (Loding, Wold, & Skavhaug, 2007). Prior to the intervention, the adolescents and their parents completed the Diabetes Quality of Life Questionnaire which measured diabetes-related impact, daily and future disease-related worries, and diabetes life satisfaction (Loding, Wold, & Skavhaug, 2007). The questionnaire was completed a total of four times within the one year study period (Loding, Wold, & Skavhaug, 2007). The researchers also measured Hemoglobin A1C values every three months during the study period (Loding, Wold, & Skavhaug, 2007). Each group meeting consisted of a warm up activity such as painting, movement, exercises, or rounds of questions unrelated to diabetes (Loding, Wold, & Skavhaug, 2007). After the warm up phase, the group meeting continued with group education and free communication by participants. All participants were given a chance to talk during the meeting (Loding, Wold, & Skavhaug, 2007). The study results showed that the adolescents had improved hemoglobin A1C
levels during the study, but this was not maintained for all participants after the study had ended (Loding, Wold, & Skavhaug, 2007). The results also showed improved relationships between the adolescents and their parents (Loding, Wold, & Skavhaug, 2007). The researchers expressed the need for further intervention studies and intervention techniques for families coping with diabetes and other chronic illnesses.

Robinson and Wright (1995) conducted a study related to families, illness and interventions. The purpose of the study was to evaluate nursing interventions for families coping with a chronic illness in one or more family members. The researchers recruited five families to participate in the study. The families all consisted of two married parents and their children (Robinson & Wright, 1995). In three of the families, a child had been diagnosed with a chronic condition. In one family, the wife/mother had been diagnosed with the chronic condition, and in another family the husband/father had been diagnosed with a chronic condition. These chronic conditions included ankylosing spondylitis, chronic fatigue syndrome, depression, diabetes, myocardial infarction, panic attacks, and tetralogy of fallot (Robinson & Wright, 1995). The study data was collected over a two year period, and focused on providing “therapeutic sessions” for each of the families (Robinson & Wright, 1995, p. 332). These therapeutic sessions focused on “bringing the family together, inviting meaningful conversation, distinguishing family strengths and resources, exploration of concerns, and putting illness problems in their place” (Robinson & Wright, 1995, p. 335). The overall goals of the interventions were to create the circumstance for change and move beyond and overcome problems. The researchers found that the therapeutic sessions brought family members closer together and gave them a feeling of unity, as well as a better understanding of one another (Robinson & Wright, 1995). After the
interventions, families were interviewed about the intervention outcomes. Family interviews showed that families felt the therapeutic sessions were effective in influencing a positive change process that improved the coping and adaptation of each of the families (Robinson & Wright, 1995). The authors explained the importance of nurses facilitating education and therapy for families coping with chronic conditions. The authors described the positive impact of nursing interventions and the importance of flexibility by nurses when carrying out interventions for different families.

Burke, Handley-Derry, & Costello et al. (1997) conducted a study to determine whether a stress-point intervention for parents of repeatedly hospitalized children with chronic conditions would reduce stress and increase coping and adaptation for those families. The authors focused on the idea that little is known about successful interventions for children with chronic conditions and their families. The study included 50 patients and their parents and utilized a pre-test and post-test method to determine the success of the intervention (Burke, Handley-Derry, & Costello et al., 1997). The scales used as measurement tools for these families included the Scales of Independent Behavior, The Vernon Post Hospital Behavior Questionnaire, The State-Trait Anxiety Inventory, The Feetham Family Functioning Survey, and The Coping Health Inventory for Parents (Burke, Handley-Derry, & Costello et al., 1997). The participants were separated into an intervention group and control group for evaluation. The participants encompassed a wide variety of medical conditions including neurodevelopmental conditions, musculoskeletal conditions, respiratory conditions, leukemias, cardiac conditions, and hematological conditions (Burke, Handley-Derry, & Costello et al., 1997). The participants in the control group received regular hospital care without any intervention. The intervention group
had phone meetings with an advanced practice nurse to focus on family perspectives, identify family concerns, and prepare families for stressful hospitalizations and chronic illness related stresses (Burke, Handley-Derry, & Costello et al., 1997). The phone meetings took place prior to hospitalization, immediately following hospital discharge, and continued for 2 weeks following hospital discharge. In addition to the meetings, nurses also mailed reminders and summaries of the phone discussions to help families focus on their goals (Burke, Handley-Derry, & Costello et al., 1997). The researchers found that at three months after hospitalization, the intervention parents had better coping and family functioning than the control group, and that intervention parents had lower anxiety levels than the parents in the control group. The study also showed that the intervention children had higher developmental gains than the control group at three months following hospital discharge (Burke, Handley-Derry, & Costello et al., 1997). The researchers explained that the overall results of the study were that stress point interventions for children and families affected by a chronic condition improves family functioning and family coping, and decreases hospitalization-induced developmental regression in children (Burke, Handley-Derry, & Costello et al., 1997).

Schultz, Schultz, & Bruce et al. (1993) studied the impact of a psychoeducational program for parents of children with intellectual disabilities. The researchers explained the increased pressures of families coping with chronic conditions and explained the need for effective family interventions. The study purpose was to empower the participants and improve family functioning. There were 54 mother-father dyads involved in this study, all of which had children with intellectual disabilities (Schultz, Schultz, & Bruce et al., 1993). The treatment group consisted of 15 dyads, and the remaining dyads participated in the control group (Schultz,
Schultz, & Bruce et al., 1993). The parents in both groups filled out portions of or answered questions from The Homes and Rah Schedule of Recent Events, The Inventory of Socially Supportive Behaviors, The Single-Item Happiness Scale, The Goldberg and Hillier General Health Questionnaire, and The Satisfaction Rating Scale (Schultz, Schultz, & Bruce et al., 1993). All measures were completed 12 months apart and occurred before and after the intervention. The psychoeducational intervention consisted of six weekly two hour visits with 12 participants in each group (Schultz, Schultz, & Bruce et al., 1993). The program curriculum consisted of strengthening family resources, family dynamics, loss and grief, communication, conflict resolution, networking, resource utilization, stress management, and relaxation techniques (Schultz, Schultz, & Bruce et al., 1993). The research showed that the parents who participated in the program had significantly less emotional distress and more positive behavioral and attitudinal outcomes than the control group one year after the program took place (Schultz, Schultz, & Bruce et al., 1993). The researchers explained that program participants were very satisfied with the program, and believed it had impacted their lives in a positive manner (Schultz, Schultz, & Bruce et al., 1993).

Information related to the effects of chronic illness on families has been studied in depth. However, successful interventions for these families has not been thoroughly studied or described. Educational nursing interventions for families coping with chronic conditions other than epilepsy may help to improve overall family functioning and quality of life. It remains to be seen whether or not these types of interventions can be applied to the family with an epileptic child. However, the effects of other chronic conditions reviewed in this paper are quite similar to
the effects of epilepsy, which means the interventions for chronic conditions other than epilepsy may be applicable to epilepsy as well.

**Results of the Literature Review**

The first portion of the literature review titled “When a child has epilepsy” showed the extreme effects of epilepsy on children and their families. The major stressors identified throughout the literature review were: a lack of knowledge about epilepsy, knowledge deficits about treatments for epilepsy, increased seizure frequency perhaps due to knowledge deficits about medication regimes, and emotional disturbances within the family. Throughout this literature review, the commonly identified effects of the stressors of epilepsy were increased depression and anxiety within the family, increased behavioral problems for children in the family, decreased quality of life and increased stress among all members of the family. In this literature review, the other themes resulting from stressors that were frequently identified for families coping with epilepsy were: compromised family adaptation, decreased social participation, increased emotional problems, and increased feelings of uncertainty.

The second portion of the literature review titled “Interventions for a child and family coping with epilepsy” showed the importance of educational interventions for children and families affected by epilepsy. While all interventions proved successful for children with epilepsy and their families, some interventions reviewed were more inclusive and tended to have an impact in more areas of adaptation and coping than other interventions. The existing research supports interventions in the form of psychoeducational programs, support groups, famoses groups, family counseling groups, educational meetings, and therapeutic alliance. Psychoeducational programs include both education about the illness and psychological
interventions. Psychoeducational programs affected families of children with epilepsy by increasing their epilepsy knowledge, increasing treatment and care adherence, decreasing seizure frequency, increasing positive coping and adaptation, and increasing the quality of life of the family as a unit. The support groups consisted of group meetings with families and children coping with epilepsy. The support groups affected families by increasing their coping and confidence related to epilepsy, and increasing positive family relationships. The famous group intervention included education for children with epilepsy and their families regarding the condition, treatment options, support systems, and possible health problems caused by epilepsy. The famous groups affected families by increasing their knowledge and coping related to epilepsy. The family counseling groups included education and discussion about the effects of epilepsy on the family. The family counseling sessions helped increase epilepsy knowledge and social behaviors, and helped to decrease anxiety in families affected by epilepsy. Therapeutic alliance interventions were focused on keeping good relationships between children with epilepsy, families, and healthcare providers. The idea of therapeutic alliance is that families and patients will be more comfortable, confident, and compliant with their care. The families who participated in therapeutic alliance had better relationships with health care providers and had increased treatment adherence. The educational intervention included education related to epilepsy as a condition and treatment options for epilepsy. The education intervention increased positive attitudes in families and increased the quality of their lives as well. While all interventions proved successful for children with epilepsy and their families, some interventions reviewed were more inclusive with education and psychological intervention techniques, and tended to have an impact in more areas of adaptation and coping than other interventions.
The third portion of the literature review titled “Interventions for a child and family coping with a chronic condition other than epilepsy” showed the significance of interventions for families of children with chronic conditions. The literature reviewed included studies on psychoeducational programs, group meetings, therapeutic sessions, and stress-point interventions. The psychoeducational programs aimed to educate and provide resources to the families to increase coping and adaptation. The results of the psychoeducation showed that families improved in the areas of illness-specific functioning, efficacy about the condition, family cohesion, peer relationships, role identification, and overall family functioning (Roblin, 2000). The psychoeducational programs also decreased the emotional stress of the families of children with chronic conditions, and the programs improved the attitudes and behaviors of the families coping with chronic conditions. The group meetings aimed to educate and allow for free communication from participants and helped to improve familial relationships and condition management. The therapeutic sessions focused on “bringing the family together, inviting meaningful conversation, distinguishing family strengths and resources, exploration of concerns, and putting illness problems in their place” (Robinson & Wright, 1995, p. 335). The results of the therapeutic sessions showed that families felt the therapeutic sessions positively changed them and improved their coping and adaptations. The stress-point intervention aimed to focus on family perspectives, identify family concerns, and prepare families for stressful hospitalizations and chronic illness related stresses (Burke, Handley-Derry, & Costello et al., 1997). The stress point intervention was successful in improving coping and family functioning and increasing developmental gains in children with chronic illnesses.
Virtually all of the interventions that were reviewed for this paper had positive effects on both the child and family coping with epilepsy or another chronic condition. However, not all of these interventions were comprehensive in providing education, social, and psychological support to the families. The programs that were more comprehensive tended to have better outcomes in all areas of family functioning. The interventions were compared and contrasted and their results were evaluated to determine how best to develop an intervention guideline for families of preschool age children with epilepsy.

**Conclusion**

The current literature regarding the coping and adaptation of children with epilepsy and their families strongly suggests that children with epilepsy and their families experience negative effects such as increased depression within the family, increased anxiety within the family, increased behavioral problems for children in the family, decreased quality of life among members of the family, increased stress among members of the family, compromised family adaptation, decreased social participation, increased emotional problems, and increased feelings of uncertainty when a family member has epilepsy. The literature reviewed also showed that epilepsy has a negative effect on family adaptation. The conclusions that can be made from the articles reviewed that relate to adaptation and families with epilepsy are that family members are affected when one family member has epilepsy, and the psychological effects of epilepsy on family members are almost always negative. This evidence suggests that healthcare providers may not always be meeting the needs of their patients and families. These effects can be clarified using the Family Stress and Coping Theory, which explains that stress is normal in families, but that, if uncompensated, it can escalate to a level of negative adaptation. The
educational intervention studies reviewed in this report had positive effects for the patients and families coping with epilepsy and other chronic illnesses. Currently, research is lacking in the area of interventions for families of children diagnosed with epilepsy. An epilepsy-related intervention guideline for health care professionals may allow advanced practitioners to improve a family’s overall family functioning, coping, adaptation, and quality of life.
CHAPTER IV: GUIDELINE AND IMPLICATIONS

Introduction

In chapter three, the relevant literature was reviewed and synthesized. Chapter four will present the intervention guideline recommendations, as well as discuss the implications for this research, strengths and limitations of this research, and the recommendations for future research on this topic.

Formulating an Intervention Guideline

Each of the interventions reviewed in this report had positive effects for families of children with epilepsy. However, in the review of the literature presented, only the psychoeducational program intervention addressed all of the common stressors of families of children with epilepsy that were identified in the literature review related to the effects of epilepsy and chronic conditions on children and families. Based on the literature reviewed, it is apparent that psychoeducational programs include aspects from all of the other interventions presented in the literature, including education, stress reduction and coping techniques, and psychological support. In the literature review, four studies showed the effectiveness of psychoeducational programs to improve epilepsy knowledge, reduce seizure frequency, improve treatment and care adherence, and improve coping and adaptation for individuals with epilepsy and their families (May & Pfafflin, 2005). All four studies were rated high or good quality evidence, and the overall strength of the empirical evidence for these studies was strong.

Other important interventions discussed in the literature included educational programs and programs for psychological support. In cases where families feel a lack of education, but seem to be adapting and coping effectively, an education only program may be a better approach.
In cases where families feel they have the education and knowledge related to epilepsy, but seem to be coping and adapting ineffectively, a psychosocial intervention without an education portion may be more appropriate. Because this paper is focused on providing a well-rounded intervention for all types of families, a more inclusive approach has been taken in formulating a guideline recommendation for families coping with epilepsy.

The intervention guideline recommendation in this paper is designed for parents or primary caregivers of preschool age children who have been diagnosed with epilepsy. Because there is currently little information about interventions for positive adaptation and coping for families of preschool age children with epilepsy, this is an important population. A target population of parents and caregivers of preschool age children with epilepsy will set the foundation for positive adaptation closer to the onset of childhood epilepsy. An intervention guideline recommendation, based on the review, strength, and quality of the literature, is presented in this chapter.

**Information About Psychoeducational Programs**

Psychoeducational programs for epilepsy provide information for families about the condition and management of the condition, provide resources and ways to manage and cope with the condition, and help children to learn about family processes and functioning when dealing with a chronic condition (May & Pfafflin, 2005). Psychoeducational programs take on many forms such as single family meetings, multifamily meetings, lecture sessions with small and large groups, individual family member meetings, or a combination of these groups or meetings (May & Pfafflin, 2005). Throughout these meetings, educators and healthcare providers discuss information about the condition to help educate children and their families. The idea of
this education is to help children and families to feel more comfortable with the condition and the effects of the condition (May & Pfafflin, 2005). It also teaches children and families about treatments for the condition, and ways to help increase adherence to treatment (May & Pfafflin, 2005).

During psychoeducational meetings, children with epilepsy and their families are also taught about ways to effectively cope and adapt while affected by epilepsy (May & Pfafflin, 2005). The literature reviewed about psychoeducational programs showed that these programs increase knowledge about the condition, decrease anxiety, increase adherence to treatment and care, increase quality of life, decrease epilepsy frequency, and increase adaptation and coping for children and families (May & Pfafflin, 2005).

**Guideline Recommendation for Practice**

This intervention guideline recommendation is based on the results of the rigorous and comprehensive literature review performed for this paper. The common stressors identified in the literature review (i.e., increased depression within the family, increased anxiety within the family, increased behavioral problems for children in the family, decreased quality of life among members of the family, increased stress among members of the family, compromised family adaptation, decreased social participation, increased emotional problems, and increased feelings of uncertainty) were used to formulate the intervention guideline. The overall goal of the program is positive adaptation for families of preschool age children with epilepsy. The target population is parents and primary caregivers of preschool age children with epilepsy. This population has been selected because there is currently little information on interventions for this age group. The intervention is focused on parents and caregivers due to the very young age of
their children with epilepsy. In the literature review for this paper, the effects of negative parental coping and adaptation on an entire family unit have been identified. Parental coping and adaptation may begin to affect children at a young age. For this reason, it is important for parents to understand the condition and the resources that are available to them to increase their adaptation and coping and decrease the potential for negative effects to occur within the rest of the family unit.

**Explanation of the Program**

Based on the review of intervention literature related to coping and adaptation of children with epilepsy and their families, a psychoeducational intervention program is recommended to improve coping and adaptation in families caring for preschool age children with epilepsy. The intervention involves a four-week (eight hour) psychoeducational program for parents and primary caregivers of preschool age children with epilepsy. This intervention program should be recommended to all families of preschool age children with epilepsy regardless of the time or length of the current epilepsy diagnosis. The four-week (eight hour) time frame was selected based on the previous research on psychoeducational programs. This time frame has shown to be more manageable for families, while still providing the necessary information and resources to help significantly improve coping and adaptation among families. The program may be conducted in single family or multi-family setting depending on family preference and/or the number of other families who can potentially participate. The program must be developed and carried out by an advanced practice health care provider whose education has included a mental health component. Table 2 below summarizes the proposed curriculum for the psychoeducational program. The program is also explained in more detail following Table 2.
Table 2. Curriculum for the Psychoeducational Program

<table>
<thead>
<tr>
<th>WEEK</th>
<th>CONTENT</th>
<th>DELIVERY METHOD</th>
<th>TIME LENGTH</th>
<th>EDUCATOR/FACILITATOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Pathophysiology/Types of Epilepsy</td>
<td>Lecture with time for open discussion</td>
<td>2 hours</td>
<td>Advanced Practice Provider</td>
</tr>
<tr>
<td>Two</td>
<td>Treatments for Epilepsy</td>
<td>Lecture with time for open discussion</td>
<td>2 hours</td>
<td>Advanced Practice Provider</td>
</tr>
<tr>
<td>Three</td>
<td>Coping and Stress Reduction Techniques</td>
<td>Lecture with time for open discussion</td>
<td>2 hours</td>
<td>Advanced Practice Provider</td>
</tr>
<tr>
<td>Four</td>
<td>Counseling/Support Group</td>
<td>Informal meeting</td>
<td>2 hours</td>
<td>Advanced Practice Provider</td>
</tr>
</tbody>
</table>

The first week of the program should be 2 hours and should include an introduction to the program, education, and discussion about epilepsy. The introduction to the program gives parents what to expect out of the program and what the goals and objectives of the program are. The advanced practice health care provider must also facilitate introductions within the group, whether it is multi-family or single family. This allows the provider to establish rapport with the family or families participating, and allows families to get to know one another and potentially establish supportive relationships. A pre-test should also be administered prior to the content of
the program to determine parents’ knowledge about epilepsy, treatments for epilepsy, and coping and stress reduction techniques. The pre-test should be short, but should address all components of the program in a question and answer format so that program effectiveness may be determined at the conclusion of the program. Week one is designed to provide information about the pathophysiology of epilepsy and the different types of epilepsy. This curriculum should then be followed by open discussion from the family or families participating. The open discussion should allow families to express their experiences with the type or types of epilepsy their children have. The open discussion should also be a time for questions from the families to the health care provider and to other families participating.

The second week of the program should be two hours and should be aimed at educating families about the most common current treatments for preschool age children with epilepsy. This education should include both pharmacologic and non-pharmacologic treatments, and should be frequently updated to ensure the education includes the most current information. This education portion should discuss the avoidance of seizure triggers and common seizure triggers that have been identified in the past. This session should also provide a time for open discussion where parents can share their own treatment experiences and the treatments that have worked best for their children. Questions from the parents should also be addressed during the open discussion portion of this session.

The third week of the program should be two hours and should include education about coping and stress reduction techniques. This portion of the program should provide several suggestions on reducing stress levels and increasing coping. Parents of children with epilepsy should be encouraged to identify their individual stressors and incorporate stress reduction
techniques that are specific to their needs. During this session, parents should be educated on ways to assess and decrease the stress levels of all children in the family, epileptic and non-epileptic, alike. Parents should also be encouraged to identify and report levels of seemingly unmanageable stress to their health care providers for further assessment and intervention.

During this session, the health care provider should facilitate an open discussion and answer questions about stress reduction and coping. Families should also be encouraged to share their effective stress reduction and coping techniques with one another.

The last week of the program should be scheduled for 2 hours, and should take the form of an informal meeting where parents can share stories, thoughts, feelings, concerns, experiences, and advice. This portion of the program should be similar to a support group meeting if it is a multi-family program, or should take the form of family counseling for a single family. The advanced health care provider should take the role of the listener and ask therapeutic questions related to the experiences of the family or families. This portion of the program should be aimed at the individual family needs and/or the specific group needs based on the other portions of the program. During the last week of the program, parents should be surveyed about the program, and should be able to rate and provide feedback about the program to ensure it is meeting the needs of families of preschool age children with epilepsy. At the end of the program, parents should also be evaluated using a post-test on the topics presented each week in order to determine the effectiveness of the intervention program. The information gathered from both the survey and the post-test should be used to make reasonable changes to the program based on the suggestions of participants and the knowledge gained by the participants.
This intervention is based on the concepts of the FSCT. Table 3 and Figure 1 below show how this intervention program relates to the FSCT.

**Table 3. Relationship Between the Intervention and the FSCT**

<table>
<thead>
<tr>
<th>Concepts from FSCT</th>
<th>Definition of the Concept</th>
<th>Examples of how the Intervention Relates to this Concept</th>
<th>Curriculum related to the Concept</th>
<th>Examples of Curriculum related to the concept</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stressors</td>
<td>Events that occur within a family that have the ability to affect or alter the functioning of the family</td>
<td>The intervention is aimed at reducing stressors within the family</td>
<td>Education about epilepsy</td>
<td>The definition of epilepsy, types of epilepsy, causes of epilepsy, and what to expect when a child has epilepsy</td>
</tr>
<tr>
<td>Appraisal</td>
<td>Determining the value of the stressor or stressors</td>
<td>Appraisal of the stressors will occur before and after the intervention</td>
<td>All curriculum from the intervention will determine how the family appraises the stressor</td>
<td>The definition of epilepsy, types of epilepsy, causes of epilepsy, and what to expect when a child has epilepsy; Treatment options (i.e., medications, surgical options); Stress reduction and coping techniques (i.e., positive thinking, meditation, support networks, stress logging, biofeedback); Open discussion</td>
</tr>
<tr>
<td>Resources</td>
<td>The properties, attributes, or skills that individuals or families possess</td>
<td>The intervention provides resources for families of children with epilepsy</td>
<td>Education about epilepsy, education about stress and coping techniques, and counseling/support group</td>
<td>The definition of epilepsy, types of epilepsy, causes of epilepsy, and what to expect when a child has epilepsy; Treatment options (i.e., medications, surgical options); Stress reduction and coping techniques (i.e., positive thinking, meditation, support networks, stress logging, biofeedback); Open discussion</td>
</tr>
<tr>
<td>Coping Strategies</td>
<td>Methods a family uses to help get through stressful situations</td>
<td>The intervention will provide coping techniques and strategies for families</td>
<td>Education about stress and coping techniques</td>
<td>Support group; Stress reduction and coping techniques (i.e., positive thinking, meditation, support networks, stress logging, biofeedback); Open discussion</td>
</tr>
<tr>
<td>Family Adaptation</td>
<td>Result of a family’s attempt to adjust and change after a stressor or stressors have occurred within the family</td>
<td>The overall goal of the intervention is to help families positively adapt to having a child with a diagnosis of epilepsy</td>
<td>All curriculum from the intervention will help determine how a family adapts to the stressors</td>
<td>The definition of epilepsy, types of epilepsy, causes of epilepsy, and what to expect when a child has epilepsy; Treatment options (i.e., medications, surgical options); Stress reduction and coping techniques (i.e., positive thinking, meditation, support networks, stress logging, biofeedback); Open discussion</td>
</tr>
</tbody>
</table>
Figure 1. Picture of the FSCT Theoretical Framework Related to the Intervention

Seizures, medication regimen, family member illness, worries about safety of the family member with seizures, timing of seizures (Stressors)

Perceived severity of epilepsy, perceived effect on the family (Primary Appraisal)

Perceived control over epilepsy, perceived emotional control, perceived family functioning (Secondary Appraisal)

Social support, knowledge, skills related to coping, dispositional coping (Resources)

Management of epilepsy and family emotions through coping and stress reduction techniques (Coping Effort and Strategies)

Goals revised based on psychoeducational program, positive or negative reappraisal of severity of epilepsy and family functioning, positive or negative attitudes and beliefs, positive or negative life and family events (Attempt at Adaptation)

Psychosocial and emotional well-being, positive family functioning, health behaviors that promote health and decrease severity of epilepsy, or negative functioning and lack of well being (Adaptation)
Table 4 below shows the common stressors of epilepsy, effective psychoeducational techniques for common stressors of epilepsy, and outcome goals for the psychoeducational program intervention presented in this paper. The overall goal of the program is positive adaptation for families of preschool age children with epilepsy.

**Table 4. Common Stressors, Interventions, and Outcome Goals of the Intervention**

<table>
<thead>
<tr>
<th>Common Stressor</th>
<th>Resource</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge deficits about epilepsy</td>
<td>Knowledge about epilepsy and effects of epilepsy</td>
<td>Greater knowledge and decreased anxiety about epilepsy and the effects of epilepsy</td>
</tr>
<tr>
<td>Knowledge deficits about treatments for epilepsy</td>
<td>Knowledge about treatments for epilepsy and the importance of treatment adherence</td>
<td>Greater knowledge and decreased anxiety about treatments for epilepsy, increased medication adherence</td>
</tr>
<tr>
<td>Increased seizure frequency</td>
<td>Knowledge about the importance of treatments for epilepsy and the consequences of poor medication adherence</td>
<td>Greater knowledge about the importance of medication adherence, and decreased seizure frequency</td>
</tr>
<tr>
<td>Emotional disturbances for the family</td>
<td>Stress reduction and coping techniques and support group</td>
<td>Decreased stress and increased coping within the family, increased quality of life for each family member</td>
</tr>
</tbody>
</table>
Cost-Effectiveness of the Program

This intervention program will have great cost-effectiveness over time. The program outcomes will allow families of children with epilepsy to decrease the financial burden of health care costs due to improvements in the overall health and well being of the child with epilepsy and his or her family. The annual cost for individuals with epilepsy and their families is approximately 15.5 billion dollars for medical costs and lost earnings and production (Center for Disease Control, 2009). This is due to physical health and mental health needs, as well as absences from work, or time taken off work for medical issues and the management of epilepsy. The major outcomes of the intervention program listed in Table 4 are greater knowledge and decreased anxiety about epilepsy and the effects of epilepsy, greater knowledge and decreased anxiety about treatments for epilepsy, greater knowledge about the importance of medication adherence, increased medication adherence, decreased seizure frequency, decreased stress and increased coping within the family, and increased quality of life for each family member. These outcomes should allow families affected by epilepsy to decrease their medical visits and necessary medical resources for both physical health and mental health issues. Parents of children with epilepsy should also spend less time away from work due to an increase in the control and successful management of epilepsy in their children. While a nominal cost would likely be charged for this intervention program, children and their families will conserve a larger amount of money over time due to the intervention program outcomes, making this a cost-effective intervention.
Limitations

A major limitation to this practice inquiry is related to the type and strength of the evidence in the literature review. Most of the intervention articles related to epilepsy were quasi-experimental designs and did not have adequate randomization. Of the four studies regarding psychoeducational programs, only one of those studies was an experimental randomized controlled trial. Newhouse et al. (2007) explained that the strongest type of evidence is an experimental design that is a randomized controlled trial. Because only one of the psychoeducational programs was a randomized controlled trial, this may be considered a limitation in this paper. Another limitation to this practice inquiry is the small number of previous research articles related to this topic. Without sufficient information related to the past use of interventions, it is unknown how the recommendations in this paper may be applicable to families of preschool age children with epilepsy.

A limitation related to the inconsistencies of the curriculum of a psychoeducational program was also identified from the literature review. All of the articles related to psychoeducational interventions had differences as to how the program was designed and what information was included. Due to these inconsistencies, the program guideline in this practice inquiry was designed using the approaches that seemed most appropriate for pediatric epilepsy in each of the different psychoeducational program articles.

The last major limitation to this practice inquiry was the lack of information about the long-term effects of a psychoeducational program on families of children with epilepsy or another chronic condition. The immediate effects of the program were clearly identified within each of the research articles reviewed; however, the long-term effects of the program were not
presented for any of the psychoeducational program studies reviewed. Because of this, it is unclear whether or not a psychoeducational program is beneficial over an extended period of time or just for a short time after the intervention has occurred. The inclusion of a pre-test and multiple post-tests over an extended period of time may address the issue of determining the long-term effects of a psychoeducational program.

**Recommendations for Future Research**

There is a great need for future research related to this topic. Currently the research related to the psychological effects of epilepsy has been thoroughly studied. However, the use of psychoeducational and psychological interventions for families coping with pediatric epilepsy has been less thoroughly studied. It is clear from previous research that pediatric epilepsy tends to have negative effects on families affected by the condition. For advanced practitioners to provide truly comprehensive care, these negative effects need to be addressed and dealt with before they lead to negative family adaptation for one or more members of the family unit. The previous research studies related to interventions for children with epilepsy tended to always have positive outcomes related to coping and adaptation. These intervention studies showed uncomplicated ways to provide families with the education and resources they need to function successfully and effectively, while coping and adapting positively to the diagnosis of epilepsy. Future studies that address the use of psychoeducation for families of children with epilepsy are crucial for the successful coping and adaptation of families who are affected by epilepsy. These types of studies provide participants with a well-rounded and comprehensive intervention that has been shown to improve overall family functioning. Because there is limited research on psychoeducational programs, future research on these programs is important. Future studies
should focus on the long-term effects of psychoeducation, and the potential need for follow-up psychoeducation after the initial program. These types of future studies will help to further develop psychoeducation and may help to improve the guideline presented in this practice inquiry.

**Significance to Healthcare Providers**

Approximately 300,000 American families include a child with epilepsy, making this a significant illness for children, their families and the advanced practice nurse (Epilepsy Foundation, 2009). Advanced practice nurses must have knowledge of psychoeducational and psychological interventions for families coping with epilepsy in order to provide resources for stress management, positive adaptation, and effective coping mechanisms. Healthcare providers should be able to educate children and their families about what to expect with a diagnosis of epilepsy, and how to effectively manage the condition and the psychosocial effects of the condition (Morrell, 2002). Psychoeducational programs have been very successful for individuals with epilepsy and other chronic conditions, and they offer a comprehensive and thorough way to provide education, emotional support, and resource support (May & Pfafflin, 2005; Snead et al., 2004). Health care providers should be aware of these programs and be willing to offer programs of this kind when applicable. Health care providers have the opportunity to largely and positively impact the lives of families of children with epilepsy.

The concept of psychoeducation is fairly simple and can be easily carried out to provide positive outcomes to families who may otherwise experience a poor quality of life filled with uncertainty and stress surrounding the diagnosis of epilepsy. The role of the health care provider, specifically the advanced practice nurse, is to provide holistic care for patients and their
families. Psychoeducation will allow health care providers to accomplish holistic patient care while improving the coping and adaptation of families of children with epilepsy.

**Summary and Conclusion**

Epilepsy is a complicated condition that currently affects approximately 2.5 million Americans. The literature reviewed shows evidence that children with epilepsy and their families may not be effectively coping and adapting due to this condition, which may lead to stress, anxiety, and a decreased quality of life. The Family Stress and Coping Theory states that families have the ability to cope under stress, but that stress can increase to a level where coping becomes impossible (Plunkett, 2003). The goal of this paper was to develop an intervention guideline that health care providers may utilize for families of children with epilepsy with the aim of stress reduction and health promotion.

There is currently a large body of information related to the effects of epilepsy on the coping and adaptation of a family unit. The current literature shows that pediatric epilepsy tends to have negative effects on the child as well as his or her family. While a large body of information exists regarding the psychosocial effects of epilepsy on families, there is little information related to psychoeducational and psychological interventions for families coping with pediatric epilepsy. The current research related to interventions and epilepsy shows progress in children with epilepsy and their families toward positive coping and adaptation. However, no intervention guideline has been derived for health care providers working with families of children with epilepsy. Health care providers for children with epilepsy must be sensitive to the potential negative psychosocial effects of epilepsy, and should provide patients and their families with the resources and information necessary for stress reduction, and
increased coping and adaptation. This paper provided a psychoeducation intervention guideline, based on previous research, for families of children with epilepsy.

Psychoeducational interventions have been shown to keep children and their families from reaching such high levels of stress that coping and adaptation become unachievable. Healthcare providers should present resources, education, and support to families affected by epilepsy to help them learn to adapt and cope with the condition. Future research should focus on different intervention techniques including psychoeducation in order to fully develop interventions that will allow for the best outcomes for these families. Without effective interventions for families coping with epilepsy, family stress may overwhelm their resources, leading to ineffective family adaptation. The evidence-based psychoeducation program guideline presented will help to provide sufficient resources for improved coping and positive family adaptation for families of children with epilepsy.
REFERENCES


